

Breast cancer-related lymphedema and sexual experiences: a mixed-method comparison study

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Abstract

Objective: Up to 40% of breast cancer survivors develop lymphedema, a chronic and sometimes disabling condition that manifests as abnormal swelling of the effected arm or hand or upper chest areas. Although the effects of lymphedema on quality of life have been well established, less well documented are the sexual experiences of breast cancer survivors with lymphedema. This study is the first to compare the sexual experiences of women with ($n = 243$) and without breast cancer-related lymphedema ($n = 109$).

Methods: A mixed-method design was used to explore both quantitatively and qualitatively the impact of lymphedema on participants' sexual experiences.

Results: Participants with breast cancer-related lymphedema reported struggles with compression garments and sexual intimacy, negative feelings involving the breast and arm, and feelings of decreased sexual desire.

Conclusions: Recommendations for healthcare professionals, social workers, and marriage and family therapists are offered with the aim of assisting women with breast cancer-related lymphedema and their sexual partners.

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Background

An estimated 41% to 94% of women who have undergone treatment for breast cancer involving damage to lymph nodes in the affected areas (e.g., surgical removal and/or biopsy of lymph nodes) are at a lifetime risk for developing breast cancer-related lymphedema (hereafter BCRL) [1–3]. Based on this percentage, the estimated prevalence of BCRL in the US population is considerable. Given the 2.9 million US women who have a history of breast cancer and the 2014 estimates of 232,240 new cases of breast cancer [1,4], an estimated 1.3 million female breast cancer survivors are likely to experience BCRL sometime during their lifetimes.

Breast cancer-related lymphedema is a chronic condition involving the accumulation of protein-rich fluid that impacts physical, functional, and psychosocial health and well-being [5–7]. Second only to breast cancer recurrence, BCRL is the most dreaded outcome of breast cancer treatment [8]. While exact causes of BCRL are unknown, evidence suggests that some cancer treatments (e.g., surgical removal of lymphatic vessels and nodes, development of tissue fibrosis following radiation treatments, infection, or surgery), which may weaken lymph nodes and the vessels carrying lymph fluid, may compromise the effectiveness of the valves in the lymph vessels and may increase risk of developing BCRL [9,10]. Although women with

BCRL report a variety of physical symptoms (e.g., pain, heaviness, tenderness, numbness, limited range of motion, and stiffness), arm swelling is the most common [11–13]. Thus, women with BCRL are unique, as they have coped successfully with the physical and emotional distress of cancer [14] only to be met with a chronic and often-physically limiting complication of their treatment [15].

Well-being and quality of life can be impacted by changes in appearance and physical limitations created by BCRL [5,6,13,15–18]. Research also suggests that for women in general, life satisfaction and quality of life are correlated with sexual satisfaction [19]. Having a satisfying sexual relationship is an important aspect of overall well-being. When the ability to establish or maintain such relationships is compromised, there can be a detrimental effect on well-being [19]. For women with BCRL, there may be several factors that can contribute to sexual dysfunction. First, the physical limitations brought on 'my lymphedema' (e.g., being unable to lift heavy objects; reducing activities that require repetitive motions with the arm; keeping the arm elevated; and protecting oneself from sunburns, insect bites, injections, or cuts that may lead to cellulitis) can create both physical and psychological challenges similar to those experienced by other women with physical limitations [6,13,15,20–22].

Second, the treatment necessary to reduce the risk of developing BCRL and to prevent flare ups in swelling

requires women to engage in time-consuming self-care and wear various types of compression garments [23,24]. For example, to reduce and control swelling associated with BCRL, women are encouraged to practice a kind of massage called manual lymph draining, wrap the arm with several layers of elastic bandages, or wear an expensive custom-made compression sleeve. Not only is this treatment restricting in terms of range of motion, but wearers are also limited physically by avoiding getting the wrapping/compression sleeve wet, dirty, or damaged [25]. Research has shown that many women with BCRL find wearing such garments impacts their body image and sense of attractiveness (Author et al., in preparation) [15,17,26]. Many women must also wear night garments that resemble arm length 'oven mitts' [27] that not only increase body temperature at night but also take up additional room in the potentially shared bed [25].

Third, BCRL, as a side effect of potentially disfiguring breast cancer treatment, can create additional changes in physical appearance and may impact on women's feelings of attractiveness and body image [17]. While researchers have extensively explored the relationship between breast cancer and sexual function [28,29], the relationship between BCRL and sexual function has not been as extensively explored as other aspects of breast cancer survivorship. This research has suggested that women with BCRL in their dominant arms experience less sexual satisfaction than those with BCRL in their non-dominant arms and that BCRL creates changes in physical appearance that can elicit feelings of unattractiveness and negative body image [17,30]. Radina et al.'s small, descriptive study that utilized interview data from women with symptoms of BCRL highlights the ways women with BCRL perceive themselves as sexual beings and how BCRL has changed their sexual behaviour. This study did not, however, offer a comparison of the sexual experiences of breast cancer survivors both with and without lymphedema.

Given that women's feelings of attractiveness and body image are tied to their sexual satisfaction [31], and that physical disabilities can be related to difficulties in establishing and maintaining sexual relationships with romantic partners [19], it stands to reason that there may be an impact on these women's perceptions of their sexuality and sexual experiences. To date, there has been no large-scale exploration of the possible differences between women with and without lymphedema with regard to their perceptions of changes in their sexual relationships related to lymphedema symptoms. The present study provides the first exploration of this type using an approach that compares these two groups of women in order to identify the existence and nature of between group differences with regard to perceived changes in sexual experiences.

Methods

Study design

A cross-sectional design with a mixed-method approach was used to collect quantitative and qualitative data. The guiding research question was as follows: Among women treated for breast cancer, in what ways does the experience of BCRL symptoms contribute to changes in sexual functioning?

To quantify the impact of BCRL symptoms on survivors' sexual experiences, participants were asked, using a force-choice question, to indicate the degree to which their BCRL symptoms affected their sexual and intimate relationship with their partner or spouse. Heideggerian hermeneutics was used to guide qualitative understanding of common meanings surrounding effects of BCRL symptoms on survivors' sexual experiences. Specifically, this study focused on interpreting the narratives of breast cancer survivors with BCRL and without BCRL. This approach allowed the researchers to develop understanding of the breast cancer survivors' lived experiences and everyday lives. The quantitative and qualitative responses of women with BCRL and without BCRL were compared in order to determine if, from the participants' perspectives, BCRL symptoms uniquely contributed to changes in their sexual function.

Ethical considerations

Institutional Review Board approval was granted for this study by New York University. The completion of the study served as the participant's consent.

Recruitment

Potential participants were included who were >21 years of age and had surgical treatment, including lumpectomy or mastectomy, sentinel lymph node biopsy, or axillary lymph node dissection. Both those with or without diagnosis or treatment for BCRL were included given that survivors without BCRL experienced at least five BCRL symptoms while those with BCRL experience 10 BCRL symptoms [2,11]. Exclusion criteria included women who (1) received no surgical treatment for breast cancer and (2) reported no current sexual partner(s).

Women were recruited to the study through the organization *StepUp-SpeakOut.org*, an online community of breast cancer survivors with BCRL or survivors at risk for BCRL. The mission of the organization is to help breast cancer survivors to reduce their risk of BCRL and promote effective management of BCRL. At data collection, there were approximately 600 patient-members of *StepUp-SpeakOut.org*. Study information and an open invitation to participate were sent to members in an electronic newsletter and were posted on the organization's

website. Interested potential participants accessed the study via the *StepUp-SpeakOut.org* website by clicking the link to the questions regarding participants' demographic information. The completion of the study served as the participant's consent. The study was open from April 20, 2010 through August 27, 2010. Of the 417 who accessed the original study, only 348 women completed the study.

Data collection procedures

Demographic data (i.e., age, race, height, weight, levels of education, marital status, and employment) were collected using the questionnaire. BCRL status was determined by the participants' confirmation that they had been diagnosed and treated for BCRL. The presence or absence of BCRL symptoms of swelling in arm and hand, breast swelling, and chest swelling was also assessed.

Participants were asked, using a force-choice question, to indicate the degree to which their BCRL symptoms affected their sexual and intimate relationship with their partner or spouse. Response choices were not at all, a little, somewhat, quite a bit, and a lot. In addition, participants were also prompted to respond to an option request to 'Please describe in detail your sexual experience in the context of your breast cancer-related lymphedema symptoms.'

Data analysis

Quantitative data were analysed using descriptive statistics. Frequencies were calculated for demographic information as well as responses to the force-choice question. Participants' narrative responses were separated into two sub-sets based on each participant's lymphedema status (i.e., with or without BCRL). Both data sub-sets were then analysed using thematic analysis. In so doing, we identified and compared patterns within similar responses in order to identify essential themes among participants' experiences [32].

Results

Participants' characteristics

Participants were 348 breast cancer survivors who enrolled in the web-based study. Of these, 243 were survivors with BCRL and 109 without BCRL. Among these, 68.4% reported to have arm and hand swelling, 42.8% breast swelling, and 45.7% chest swelling. Participants who did not respond to the forced-choice question regarding the degree to which their BCRL symptoms affected their sexual and intimate relationships with their partner or spouse were excluded from data analysis (BCRL = 183; without BCRL = 86). Participants (BCRL = 7; without BCRL = 2) who reported either not having a partner or having an unavailable partner (e.g., lived in nursing home

or dealing with his own physical health issues) were also eliminated from analysis. The final sample consisted of forced-choice and narrative responses for 176 survivors with BCRL and 84 survivors without BCRL. As shown in Table 1, the majority of participants ranged in age from 45 to 59 years (BCRL = 64.2%; without BCRL = 66.3%) with the highest percentage ranging from 50 to 54 years (BCRL = 22.7%; without BCRL = 30.1%). Most of the participants had at least some college education (BCRL = 86.3%; without BCRL = 89.2%), were married (BCRL = 73.9%; without BCRL = 81.9%), and were White (BCRL = 92.6%; without BCRL = 97.6%).

A frequency analysis of participants' responses to the forced-choice question appears in Figure 1. No effect of their symptoms on their sexual and intimate relationships was reported by 41.2% of those without BCRL and 42.6% of those with BCRL. Participants with BCRL were more likely to report greater effects of their BCRL symptoms on their sexual and intimate relationships than those without BCRL.

Table 1. Summary of participant characteristics

Characteristic	Participants with BCRL	Participants without BCRL
	(n = 176)	(n = 84)
Age (years)		
35–39	8 (4.6%)	2 (2.4%)
40–44	18 (10.2%)	8 (9.6%)
45–49	34 (19.3%)	14 (16.9%)
50–54	40 (22.7%)	25 (30.1%)
55–59	39 (22.2%)	16 (19.3%)
60–64	13 (7.4%)	13 (15.7%)
65–69	20 (11.4%)	5 (6.0%)
70–74	2 (1.1%)	0 (0.0%)
75–79	1 (0.6%)	0 (0.0%)
Highest level of education		
Elementary school	1 (0.6%)	0 (0.0%)
Middle school	1 (0.6%)	0 (0.0%)
High school	16 (9.1%)	7 (8.4%)
Technical school	5 (2.8%)	2 (2.4%)
Partial college	34 (19.3%)	14 (16.9%)
College graduate	56 (31.8%)	27 (32.5%)
Graduate degree	62 (35.2%)	33 (39.8%)
Marital status		
Married	130 (73.9%)	68 (81.9%)
Partnered/permanent relationship	9 (5.1%)	5 (6.0%)
Divorced/separated/no longer partnered	20 (11.4%)	5 (6.0%)
Widowed	7 (4.0%)	0 (0.0%)
Single/never married	8 (4.5%)	5 (6.0%)
Racial/ethnic background		
Asian	3 (1.7%)	0 (0.0%)
Black/African American	4 (2.3%)	1 (1.2%)
White	163 (92.6%)	81 (97.6%)
Hispanic	1 (0.6%)	1 (1.2%)
Other	3 (1.7%)	0 (0.0%)

BCRL, breast cancer-related lymphedema.

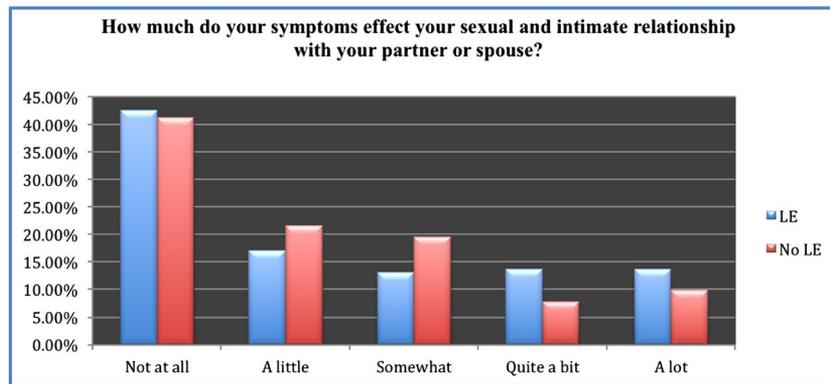


Figure 1. Impacts of lymphedema symptoms on sexual relationships

Participants without breast cancer-related lymphedema ($n = 84$)

Thirteen participants without BCRL offered narrative responses. The most common ($n = 7$) statements about changes in sexual relationships for these women centred around decreased sexual activity due to physical symptoms that they attributed to breast cancer (e.g., ‘unpleasant feeling to touch over right breast’, ‘severe vaginal dryness’, and ‘sexual intercourse is now extremely painful’). Also common among was a decrease in sexual desire or libido ($n = 3$) and concerns about physical appearance as a result of breast cancer surgery ($n = 3$).

Participants with breast cancer-related lymphedema ($n = 176$)

Participants with BCRL who offered a narrative response ($n = 47$) to two overarching themes were identified: Effects of Garments and Negative Feelings about Sex/Intimacy.

Effects of garments

Participants ($n = 11$) reported two predominate ways required garments served as barriers to sexual activities. First were ways that wearing compression garments was perceived as a barrier or an annoyance during sexual activity. Second were ways that participants’ perceptions of themselves as sexy were impacted by wearing compression garments.

Hindering intimacy

One way participants ($n = 7$) reported issues with compression garments as factors in their sexual activity was that they found garments to hinder their ability to be physically intimate with partners. One example comes from Linda (60–64 years of age, married, White) who reported that her BCRL symptoms have ‘a little’ affect on her sexual and intimate relationship with her husband, ‘The night sleeve slows down our love making a bit as does taking off day garments should things get amorous.’ Linda

reported only experiencing ‘a little’ swelling in her arm/hand. Similarly, Mary (45–49 years of age, married, Black) stated, ‘It’s difficult to be spontaneous with bandages/night garment on.’ Mary reported that her BCRL symptoms had ‘somewhat’ of an affect on her sexual and intimate relationship. Mary also reported experiencing some swelling in her arm/hand, breast, and chest wall.

Effects on ‘feeling sexy’

The second way that compression garments seems to affect participants’ sexual experiences is the role that garments play in body image and their feelings of attractiveness ($n = 6$). For example, Susan (50–54 years of age, married, White) said, ‘[it’s] kind of hard to feel or look sexy while wearing compression bandages or a night sleeve!’ Susan reported that the BCRL symptoms she experienced had ‘quite a bit’ of an affect on her sexual and intimate relationship. She also reported ‘quite a bit’ of swelling in her hand/arm as well as some swelling in her breast and chest wall. Another example comes from Deborah’s (55–60 years of age, married, White) statement that ‘going to bed with the ‘oven-mitt’ on is not too attractive!’ Deborah reported that her BCRL symptoms had ‘a little’ affect on her sexual relationship. She also reported experiencing some swelling in her arm/hand, breast, and chest wall.

Negative feelings about sex/intimacy

Participants reported both positive and negative feelings about sexual and intimate relationships. Just four participants explicitly expressed positive feelings and one of those stated that her sexual relationship with her husband had not changed as a result of cancer. Instead, many participants ($n = 19$) reported negative feelings about sexual and intimate relationships. They attributed this to either their BCRL or related to their breast cancer treatment/experiences.

Breast cancer-related lymphedema-related

Participants ($n=11$) who attributed negative feelings about their sexual relationships to their BCRL symptoms described how pain, discomfort, and concerns about their arms and/or BCRL have impacted their sexual and intimate relationships. In the case of Jennifer (35–39 years of age, married, White), it was not just the compression garments but also the BCRL symptoms that she attributed to changes in her sexual experiences. ‘My garments and physical discomfort have a severe negative effect on my sexual desire.’ Jennifer reported that her BCRL symptoms had ‘a lot’ of affect on her sexual and intimate relationship. She also reported experiencing some swelling in her arm/hand but ‘quite a bit’ of swelling in her breast and chest wall.

Patricia (55–59 years of age, married, White) reported that her BCRL symptoms at ‘a lot’ of affect on her sexual and intimate relationship. She stated, ‘I feel as if I look like a blow up doll...all the right parts, but no feelings... I SO WANT to WANT to have sex...very upsetting for me...’ Patricia reported experiencing some swelling in her arm/hand.

Karen (45–59 years of age, married, White) explains how both the breast cancer treatments and BCRL symptoms have had ‘quite a bit’ of an affect on her sexual and intimate relationship,

We had a great sex life. Between the anti-estrogen treatments and the lymphedema, brachial plexus neuropathy, it has gone from a 9 to a 2. Sometimes I feel like my husband has gone from being my lover to being my nurse’s aide. He helps me get my garments on, do massage and monitor my slowly healing arm. I guess I should feel grateful I have any sex life at all.

Although Karen reported that these symptoms had ‘quite a bit’ of affect on her sexual experiences, she reported ‘a little’ swelling in her arm/hand and chest wall.

Breast cancer-related

Some participants ($n=8$) described how their breast cancer treatment and/or experiences, in general, had an impact on their sexual and intimate relationships. While these participants reported BCRL symptoms, they did not mention how their BCRL-specific symptoms had an affect on their sexual and intimate relationships. Rather, in describing the affect of symptoms on their sexual experiences, these participants focused on their breast cancer alone. For example, Donna (50–54 years of age, married, White) explained,

[My sex life is] affected because I am not the same person physically as I was before, and I never will be again. The

sensations from the mastectomy make it very hard to let my husband touch me there because the feeling is very creepy and just not right, not pleasurable at all.

Similarly, Barbara (50–54 years of age, married, White) reports that

Since beginning hormonal therapy with Tamoxifen and now Femera my libido is nil. I am too young to feel this way. It was difficult enough having to deal with a mutilated body, then hair loss. When you finally get through all of that you end up with no desire because of the hormonal therapy. This needs to change. There has to be another way to fight this disease that doesn’t affect the quality of life. Oh, I forgot, when I do participate in an intimate relationship the joint pain is unbearable.

Barbara reported that she experienced ‘quite a lot’ of affect on her sexual and intimate relationship. She also reported some swelling in her arm/hand. Barbara’s reference to her mutilated body is open to interpretation, as she was not specific about this perception of her body as being the result of breast cancer surgery or the deformity she experienced related to lymphedema.

Conclusions

The study reported here offers the first comparison of the sexual experiences of breast cancer survivors both with and without BCRL. Previous research has predominately focused on breast cancer survivors’ sexual experiences in general [33–35] or on exploring *only* the experiences of participants with BCRL [17,30]. To date, no study has offered a comparison of breast cancer survivors’ sexual experiences in which the presence of BCRL is the focus of comparison. Such a comparison is useful in order to provide insight regarding the ways in which BCRL can have a unique impact on breast cancer survivors’ sexual relationships. As discussed earlier, women’s perceptions of their body image and disability status, both of which can be effected by breast cancer and BCRL, are linked to sexual satisfaction and quality of life [19,20,31].

The results of this study suggest that in comparison to patients without BCRL, those with BCRL report far more challenges with their sexual relationships. While similar proportions of both groups reported no effect of their symptoms on their sexual experiences, what is notable are the differences between the two groups in the distribution of responses among the remaining response categories. That is, those with BCRL reported more highly concentrated responses in the ‘quite a bit’ and ‘a lot’ categories than those without BCRL. These findings represent a noteworthy and clinically relevant difference between these two groups of breast cancer patients. Previous research, which focused only on participants with BCRL,

support this finding that BCRL can be distressing for patients and can have influence on their sexual experiences [17,30]. The comparison data used in this study underscore the central role that BCRL can play in the sexual experiences of breast cancer survivors.

Patients with BCRL reported struggles with garments used to maintain fluid pressure on the affected arm with regard to sexual intimacy. Specifically, participants reported that these garments got in the way during sexual activity or made them feel less attractive. As also reported by Radina et al., these findings suggest that patients with BCRL may no longer feel sexy because of their BCRL symptoms and garments. Interestingly, Radina et al.'s participants' references to body image and appearance were limited to their experiences with compression garments and night sleeves [17]. Based on previous studies with this population [17,18], as well as research regarding women and physical disabilities [19], we anticipated that participants would also mention how their appearance related to swelling in the affected arm, neck, chest, back, or hand might also impact their feelings of sexiness.

Participants with BCRL also reported negative feelings toward sexual activity that they attributed to the physical challenges and limitations they experienced because of their BCRL symptoms (e.g., pain, discomfort, and concerns about making BCRL worse or injuring themselves). This finding reflects other research regarding women and physical disabilities where physical limitations create both physical and psychological challenges [6,13,20,36]. For example, Plach et al. studied the experiences of women experiencing another physical disability and disfiguring chronic condition, rheumatoid arthritis (RA) [36]. Based on their research, the authors identified a theme for these women's experiences that they termed corporeality—'being one's body' (p. 142). Within this term, they identified three sub-themes in their qualitative study: 'relating to a noncompliant body, body out of synch, and private body made public' (p. 142). In many ways, the experiences of women with RA appear similar to those of women with BCRL. Specifically, both women with RA and women with BCRL have been found to report the following: (1) feeling challenged by a body that no longer functions in the ways it used to or how they now want it to, (2) coping with the experience of pain and frustration, and (3) being self-consciousness of the disfiguring brought on by their chronic conditions. Such similarities between the experiences of these two groups of patients with chronic conditions are noteworthy. That is, researchers and clinicians who work with BCRL patients may find that the experiences of patients with RA useful in informing future research and treatment protocols—particularly with regard to the mental health needs of their patients.

This finding of coping with physical limitations of BCRL also reflects previous research regarding how

women with BRCL cope with their condition in their everyday lives [5]. Radina labels this as embodied limitation, which is defined as 'a heightened sense of awareness and caution...concerning...physical activities as well as a sense of frustration with the limitations' (p. 454) [18]. Both the terms corporeality and embodied limitations could be applied to these participants' sexual experiences in order to understand how their sense of their physical condition may influence their sexual activities. That is, using these terms to frame the experiences of women with BRCL helps to focus attention on the embodied and subjective nature of illness experience in order to inform future research as well as clinical practice that best meets the needs of patients with BRCL.

For participants without BRCL (breast cancer only), most commented on changes in their sexual relationships as decreased sexual activity due to physical symptoms they attributed to the breast cancer, decreased sexual desire or libido, and concerns about physical appearance as a result of breast cancer surgery. The findings regarding decreased sexual activity and libido reflect previous research [37] and may be interpreted as a result of fatigue that is often experienced by patients undergoing chemotherapy or radiation treatments [38,39]. In addition to potential treatment-induced sexual dysfunction, some participants reported feelings of apprehension for engaging in sexual activity related to their physical appearance. This finding, although not reported with great frequency among these participants, reflects previous research on breast cancer and sexuality that has focused on the often-disfiguring effects of breast surgery as treatment for breast cancer [35,38,40,41].

One particularly interesting and potentially confusing finding from this comparison study is the percentage of participants that reported no effect of their BRCL symptoms on their sexual and intimate relationships (without BRCL=41.2%; BRCL=42.6%). These percentages are quite a bit lower than those reported by Kornblith and Ligibel in which they estimate that between 70% and 80% of breast cancer survivors do not report experiencing sexual dysfunction after being treated for breast cancer [42]. The data we present here suggest that roughly 58% of these breast cancer survivors reported experiencing at least some effects of BRCL symptoms on their sexual relationships. Kornblith and Ligibel estimated that this percentage should be closer to 20% or 30% [42]. While these data are not entirely compatible, given different methods of data collection, it should be noted that researchers might be underestimating the impact of breast cancer as well as BRCL on the sexual lives of survivors. In addition, patients might feel more comfortable to disclose this sensitive issue. In the era of online technology, future researchers should explore the effectiveness of online evaluation of sexuality and building virtue community to deliver intervention in comparison to traditional

evaluation and intervention delivery by healthcare professionals or researchers.

Limitations, recommendations for future research, and implications

We found that women with breast cancer but without BRCL, and to a small degree those who do, report decreased sexual activity due to physical changes resulting from breast cancer treatment and decreased libido. Given that the focus of this study was on the role of BRCL on sexual experiences, data were not analysed regarding cancer treatment. Thus, the connection between the experiences of these participants who did not have BRCL and sexual dysfunction related to treatment-induced fatigue is not definitive. Certainly, future analyses of these data, as well as future studies with these populations, should include exploration of this issue.

Prior to data analysis, we had expected to find that participants would make references to how BRCL changes their appearance in terms of swelling in the affected arm, neck, chest, back, or hand. We also expected that participants would cite this as concerns in terms of body image and feelings of attractiveness. Unexpectedly, this was not the case. Future research should explore more explicitly the potential connection between BRCL, body image, and sexual experiences.

Certainly, there may be other factors related to breast cancer and/or BRCL that may play a role in breast cancer survivors' sexual experiences. These include whether the participant had breast reconstruction, if BRCL is present

in the dominant or non-dominant arm, type of cancer and/or BRCL treatment, and time since onset of BRCL. All of these factors should be explored in order to better understand BRCL patients' subjective experiences of their chronic condition.

Body image and sexual relationships are not often topics of discussion between patients, their intimate romantic partners, and healthcare providers [40]. These findings should be utilized by healthcare professionals, social workers, family life educators, sex educators, and marriage and family therapists to assist patients with BRCL and their sexual partners in coping with this chronic condition. Ultimately, research-based educational and therapeutic resources should be made available to patients and couples in order to help cope with changes in sexual experiences brought on 'my lymphedema'.

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Conflict of interest

The authors have declared no conflict of interest.

References

- American Cancer Society. Breast Cancer Facts & Figs. 2011–2012. American Cancer Society, Inc: Atlanta, 2014. <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-030975.pdf> 2013
- Armer JM, Stewart BR. Post-breast cancer lymphedema: incidence increases from 12 to 30 to 60 months. *Lymphology* 2010;**43**:118–127.
- Ferlay J, Bray F, Pisani P, Parkin DM. GLOBOCAN 2002: Cancer Incidence, Mortality and Prevalence Worldwide, IARC Press: Lyon, France, 2004.
- Howlader N, Noone AM, Krapcho M, Garshell J, Neyman N, Altekruse SF, Kosary CL *et al.* (eds). SEER Cancer Statistics Review, 1975–2010. National Cancer Institute. Bethesda, MD: http://seer.cancer.gov/csr/1975_2010/, based on November 2012 SEER data submission, posted to the SEER web site, April 2013.
- Radina ME, Armer JM. Surviving breast cancer and living with lymphedema: resiliency among women in the context of their families. *J Fam Nurs* 2004;**10**(4):485–505. DOI:10.1177/1074840704269847.
- Pyszel A, Malyszczak K, Pyszel K, Andrzejak R, Szuba A. Disability, psychological distress and quality of life in breast cancer survivors with arm lymphedema. *Lymphology* 2006;**39**(4):185–192.
- Voogd AC, Ververs JM, Vingerhoets AJ, Roumen RM, Coebergh JW, Crommelin MA. Lymphoedema and reduced shoulder function as indicators of quality of life after axillary lymph node dissection for invasive breast cancer. *Br J Surg* 2003;**90**(1):76–81. DOI:10.1002/bjs.4010.
- Bernas M, Askew R, Armer J, Cormier J. Lymphedema: how do we diagnose and reduce the risk of this dreaded complication of breast cancer treatment? *Curr Breast Cancer Rep* 2010;**2**(1):53–58. DOI:10.1007/s12609-010-0009-1.
- Kwan W, Jackson J, Weir LM, Dingee C, McGregor G, Olivotto IA. Chronic arm morbidity after curative breast cancer treatment: prevalence and impact on quality of life. *J Clin Oncol* 2002;**20**(20):4242–4248. DOI:10.1200/JCO.2002.09.018.
- Mortimer PS. The pathophysiology of lymphedema. *Cancer* 1998;**83**(12 Suppl):2798–2802. DOI:10.1002/(SICI)1097-0142(19981215)83:12B+<2798::AID-CNCR28>3.0.CO;2-E.
- Armer JM, Radina ME, Porock D, Culbertson SD. Predicting breast cancer-related lymphedema using self-reported symptoms. *Nurs Res* 2003;**52**(6):370–379.
- Coster S, Poole K, Fallowfield LJ. The validation of a quality of life scale to assess the impact of arm morbidity in breast cancer patients post-operatively. *Breast Cancer Res Treat* 2001;**68**(3):273–282. DOI:10.1023/A:1012278023233.
- Thomas-MacLean R, Miedema B, Tatemichi SR. Breast cancer-related lymphedema: women's experiences with an underestimated condition. *Can Fam Physician* 2005;**51**(2):246–247. Retrieved March 4, 2014: <http://www.cfp.ca/content/51/2/246.full.pdf+html> 1
- Passik SD, McDonald MV. Psychosocial aspects of upper extremity lymphedema in women treated for breast carcinoma. *Cancer* 1998;**83**(12):2817–2820. DOI:10.1002/(SICI)1097-0142(19981215)83:12B+<2817::AID-CNCR32>3.0.CO;2-2.
- Honor A. The information needs of patients with therapy-related lymphoedema. *Cancer Nurs Pract* 2009;**8**(7):21–26. DOI:10.7748/cnp2009.09.8.7.21.c7257.
- Radina ME, Armer JM. Post breast cancer lymphedema and the family: a qualitative

- investigation of families coping with chronic illness. *J Fam Nurs* 2001;**7**:281–299. DOI: 10.1177/107484070100700305
17. Radina ME, Watson WK, Faubert K. Breast cancer-related lymphoedema and sexual relationships in mid and later life. *J Lymphoedema* 2008;**3**(2):20–37. Retrieved March 4, 2014: http://britishjournaloflymphoedema.com/journal/0302_sexual.pdf
 18. Radina ME. Breast cancer-related lymphoedema: implications for family leisure participation. *Fam Relat* 2009;**58**(4):445–459. DOI:10.1111/j.1741-3729.2009.00565.x.
 19. Moin V, Durdevany I, Mazor D. Sexual identity, body image and life satisfaction among women with and without physical disability. *Sex Disabil* 2009;**27**:83–95. DOI:10.1007/s11195-009-9112-5.
 20. Galvin RD. Researching the disabled identity: contextualising the identity transformations which accompany the onset of impairment. *Sociol Health Illn* 2005;**27**:393–413. DOI:10.1111/j.1467-9566.2005.00448.x.
 21. Meiklejohn JA, Heesch KC, Janda M, Hayes SC. How people construct their experience of living with secondary lymphoedema in the context of their everyday lives in Australia. *Support Care Cancer* 2013;**21**(2):459–466. DOI:10.1007/s00520-012-1534-4.
 22. Ridner SH. Breast cancer lymphedema: pathophysiology and risk reduction guidelines. *Oncol Nurs Forum* 2002;**29**(9):1285–1293. DOI:10.1188/02.ONF.1285-1293.
 23. Ridner SH, Bonner CM, Deng J, Sinclair VG. Voices from the shadows: living with lymphoedema. *Cancer Nurs* 2012;**35**(1):E18–E26. DOI:10.1097/NCC.0b013e31821404c0.
 24. Ridner SH, Fu MR, Wanchai A, Steward BR, Armer JM, Cormier JN. Self-management of lymphedema: a systematic review of the literature from 2004 to 2011. *Nurs Res* 2012;**61**(4):291–299. DOI:10.1097/NNR.0b013e31824f82b2.
 25. Fu MR. Cancer survivors' views of lymphedema management. *J Lymphoedema* 2010;**5**(2):39–48.
 26. Fu MR, Rosedale M. Breast cancer survivors' experience of lymphedema related symptoms. *J Pain Symptom Manage* 2009;**38**(6):849–859. DOI:10.1016/j.jpainsymman.2009.04.030.
 27. Step Up, Speak Out. Standard treatment of lymphedema—night time garments. Retrieved March 4, 2014: http://www.stepup-speakout.org/nightgarments_for_lymphedema.htm
 28. Figueiredo MI, Cullen J, Hwang Y, 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**(19):4002–4009. DOI:10.1200/JCO.2004.07.030.
 29. Gould J, Grassau P, Manthorne J, Gray RE, Fitch MI. 'Nothing fit me': nationwide consultations with young women with breast cancer. *Health Expect* 2006;**9**(2):158–173. DOI:10.1111/j.1369-7625.2006.00383.x.
 30. Passik SD, Newman M, Brennan M, Tunkel R. Predictors of psychological distress, sexual dysfunction and physical functioning among women with upper extremity lymphedema related to breast cancer. *Psycho-Oncology* 1995;**4**:255–263. DOI:10.1002/pon.2960040402.
 31. Pujols Y, Seal BN, Meston CM. The association between sexual satisfaction and body image among women. *J Sex Med* 2010;**7**(2 Pt 2):905–916. DOI:10.1111/j.1743-6109.2009.01604.x.
 32. Braun V, Clark V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**:77–101. DOI:10.1191/1478088706qp063oa.
 33. Ganz PA, Desmond KA, Leedham B, Rowland JH, Meyerowitz BE, Belin TR. Quality of life in long-term, disease free survivors of breast cancer: a follow-up study. *J Natl Cancer Inst* 2002;**94**(1):39–49. DOI:10.1093/jnci/94.1.1.
 34. Rosedale M, Fu MR. Confronting the unexpected: temporal, situational, and attributive dimensions of distressing symptom experience for breast cancer survivors. *Oncol Nurs Forum* 2010;**37**(1):E28–E33.
 35. Yurek D, Farrar W, Anderson BL. Breast cancer surgery: comparing surgical groups and determining differences in postoperative sexuality and body change stress. *J Consult Clin Psychol* 2000;**68**(4):697–709. DOI:10.1037//0022-006X.68.4.697.
 36. Plach SK, Stevens PE, Moss VA. Corporeality: women's experiences of a body with rheumatoid arthritis. *Clin Nurs Res* 2004;**13**(2):137–155.
 37. Fu MR, Chen CM, Haber J, Guth AA, Axelrod D. The effect of providing information about lymphedema on the cognitive and symptom outcomes of breast cancer survivors. *Ann Surg Oncol* 2010;**17**(7):1847–1853.
 38. Henson HK. Breast cancer and sexuality. *Sex Disabil* 2002;**20**(4):261–275. DOI:10.1023/A:1021657413409.
 39. Monga U, Garber S, Kerrigan AJ, Monga TN. Pre- and post-radiotherapy sexual functioning in prostate cancer patients. *Sex Disabil* 2002;**19**:239–252. DOI:10.1023/A:1017901224691.
 40. Schover LR. The impact of breast cancer on sexuality, body image, and intimate relationships. *CA Cancer J Clin* 1991;**41**(2):112–120. DOI:10.3322/canclin.41.2.112.
 41. Sheppard L, Ely S. Breast cancer and sexuality. *Breast J* 2008;**14**(2):176–181.
 42. Kornblith AB, Ligibel J. Psychosocial and sexual functioning of survivors of breast cancer. *Semin Oncol* 2003;**30**(6):799–813. DOI:10.1053/j.seminoncol.2003.08.025.