



Patient Perceptions of Barriers to Self-Management of Breast Cancer-Related Lymphedema

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Abstract

Breast cancer survivors are at lifetime risk for the development of breast cancer-related lymphedema, a chronic, potentially debilitating condition that requires life-long symptom management. Suboptimal self-management rates suggest that health care providers may not be offering educative-support options that are customized to patient-perceived needs. An Institutional Review Board-approved focus group ($N = 9$) and mailed surveys ($N = 15$) were used to identify (a) barriers to lymphedema self-management, (b) how breast cancer survivors with lymphedema defined education and support, (c) what type of education and support they had received, and (d) what kind of education and support they wanted. Physiological, psychological, and psychosocial factors were identified as barriers to successful lymphedema self-management. One of the main barriers identified was lack of education about lymphedema treatment and risk reduction. In addition, more than half defined support as “prescriptions” and “referrals”; therefore, it is unclear whether patients were exposed to support other than medical treatment.

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An estimated 252,710 new breast cancer cases will be diagnosed in 2017, and an estimated 3 million women are living with breast cancer in the United States (American Cancer Society, 2017; Howlader et al., 2017). Of the 3 million breast cancer survivors in the United States, recent data demonstrate that 10% to 30% of breast cancer survivors will develop breast cancer–related lymphedema (BCRL), despite surgical advances in the treatment of breast cancer (e.g., sentinel lymph node biopsy [SLNB]; Miller et al., 2014). Armer and Stewart (2010) reported from 41% to 94% may develop BCRL within 60 months of surgery; however, this varies depending on the methods of assessment and criteria used for diagnosis of lymphedema. Findings reported from a systematic review of 72 studies suggested that more than one in five breast cancer survivors will develop BCRL and 21% of breast cancer survivors worldwide will develop BCRL (DiSipio, Newman, Rye, & Hayes, 2013).

BCRL is a chronic, potentially debilitating condition that restricts the flow of lymphatic fluid, causing swelling of the soft tissues and extracellular spaces (Lasinski et al., 2012). It occurs most often in women who have undergone axillary lymph node dissection (ALND), SLNB, radiation therapy, and/or certain chemotherapy agents for treatment of breast cancer (Armer et al., 2013). Breast cancer survivors may develop lymphedema within days or up to 20 years postoperatively. Once symptoms appear, lymphedema becomes a lifelong condition that requires ongoing management of symptoms with daily treatment regimens to prevent progression and manage serious symptoms (Armer et al., 2008). Early detection and treatment of lymphedema offers the greatest success in BCRL management and potential cost savings with conservative regimens (DiSipio et al., 2013; National Lymphedema Network, n.d.).

Combined Decongestive Therapy (CDT) is considered the “gold standard” by experts who treat BCRL. Phase I of CDT consists of an intensive reductive phase by a specialty-trained therapist followed by Phase II for maintenance, in which patients are instructed in self-care, including risk-reduction activities; self-manual lymphatic drainage; skin care; identification of the signs and symptoms of infection; proper fit, care and regimen for compression garments; and the importance of good nutrition, exercise, and weight management (Lasinski, 2013; Lasinski et al., 2012; National Lymphedema Network, n.d.; Ridner et al., 2012). Patient adherence to BCRL self-management in Phase II is very important, and failure to control symptoms of BCRL may lead to repeated episodes of cellulitis and progressive trophic skin

changes (Alcorso, Sherman, Koelmeyer, Mackie, & Boyages, 2016; International Society of Lymphology, 2016). After initial treatment, education about BCRL and the optimization of self-management practices should be integral parts of treatment (Douglass, Graves, & Gordon, 2016; Stuiver, Ten Tusscher, & McNeely, 2017).

A review of the literature over the last two decades reports BCRL self-management adherence rates vary depending on the treatment modalities studied; however, there is consensus that patient adherence rates are suboptimal. Early work by Boris, Weindorf, and Lasinski (1997) reported a relationship between patient adherence and limb reduction, reporting an evaluation of patients with 25%, 50%, and 75% compliance showed increased reductions with increasing compliance. More recently, in a study of 141 participants in the Physical Activity and Lymphedema (PAL) trial, Brown, Cheville, Tchou, Harris, and Schmitz (2014) reported suboptimal BCRL self-management adherence rates with only 31% of participants reporting adherence rates of $\geq 75\%$. A secondary analysis of the PAL trial data reported self-adherence rates of 128 women as follows: 16 (13%) reported a mean of less than 25% of adherence, 36 (28%) reported a mean of 25% to 49% of adherence, 40 (31%) reported a mean of 50% to 74% of adherence, and 36 (28%) reported a mean of 75% to 100% of adherence (Brown et al., 2015). Individualized modalities may have higher adherence rates; however, most BCRL regimens will involve three to 12 modalities, depending on symptom severity. In a study of 166 women with BCRL, participants reported adhering to a mean of five out of seven behaviors, with 19.5% of participants adhering to all seven modalities prescribed in their regimens (Alcorso et al., 2016).

Physiological, psychological, and psychosocial factors are barriers to successful lymphedema self-management (Fu et al., 2013; Ridner, Dietrich, & Kidd, 2011). In a study of breast cancer survivors with BCRL ($n = 74$) compared with breast cancer survivors without BCRL ($n = 75$), Ridner and Dietrich (2008) identified obesity (body mass index [BMI] > 30), orthopedic problems, hypertension, and arthritis as more prevalent in the lymphedema group, impacting adherence to BCRL self-management as well as quality of life (QOL). With respect to BCRL patients ≥ 70 years of age, Bellury et al. (2013) found an interaction between symptom burden and comorbidities in 39% of older breast cancer survivors studied ($N = 759$). Contributing factors to psychological and psychosocial barriers were identified in a systematic review of 23 studies (11 quantitative; 12 qualitative), which included lack of social, family, and professional support; time-consuming daily lymphedema care; lack of public sensitivity to the problem; insufficient health insurance; and financial burdens (Fu & Kang, 2013; Fu et al., 2013). The lack of evidence-based research relevant to BCRL risk reduction, treatment, education,

and support creates a wide variety of practice patterns and clinical uncertainty. For many breast cancer survivors, developing BCRL is a prevalent fear, second only to breast cancer recurrence (Bernas, Askew, Armer, & Cormier, 2010).

Patients have concerns about the lack of knowledge about BCRL among health care providers and the inconsistency of BCRL education, especially regarding risk-reduction activities and treatment (Cal & Bahar, 2016; Kwan et al., 2012). The objectives of this study with female breast cancer survivors diagnosed with BCRL are to better understand the barriers they face with BCRL and gain insight into their perceptions of education and support.

BCRL Education and Support

There are limited studies relevant to BCRL education and support, and with no standardization, practice patterns vary. Many times, it is the lack of BCRL knowledge on the part of health care providers that limits adequate patient education. The Breast Cancer and Knowledge Study (BC LINK) utilized an online survey ($N = 887$ of 2,469 invited) of oncologists, primary care physicians, surgeons, and nurse practitioners to assess BCRL knowledge, education, and referral patterns. Oncologists and surgeons scored highest in all categories, with only 36.2% of primary physicians reporting ever having made referrals for BCRL. In addition, it was reported that nurse practitioners were less likely to make referrals for BCRL than physicians (Tam et al., 2012). With breast cancer survivors living longer, many oncologists and surgeons are transitioning their patients back to primary care physicians for follow-up through long-term survivorship; therefore, a problem may exist if primary care physicians lack knowledge regarding long-term treatment effects, such as BCRL. Patients are voicing their dissatisfaction with (a) not being offered BCRL education by health care providers, (b) inadequate information, and/or (c) conflicting information (Cal & Bahar, 2016; Kwan et al., 2012).

Few studies examine the format and types of education that are favored by patients with lymphedema. In a study comparing patients with primary and secondary lymphedema, dedicated websites (76%) were rated as the most commonly used source for information by patients with primary or secondary lymphedema (Deng et al., 2013). Second to dedicated websites, top information sources were physicians and primary health care providers (55.5%), support groups on the Internet (33.6%), and family and friends (32.1%) (Deng et al., 2013). Although physicians and primary health care providers were listed as the second most common education source, it was also reported that the quality of information was moderate and patients felt marginalized by

health care providers who were not well informed about lymphedema (Deng et al., 2013). Findings from this study suggested that internet users may in fact be seeking information about lymphedema on their own due to the lack of resources provided. It is not clear whether patients with secondary lymphedema were provided information at the time of their cancer diagnosis or at the time lymphedema symptoms emerged. Sufficiency and timeliness of information is another area that needs more study. Many patients report receiving BCRL education and information from their lymphedema therapist after BCRL symptoms emerge, thereby denying patients the benefits of education about lymphedema risk and risk-reducing activities, prospective surveillance, and early diagnosis (Ostby et al., 2014).

Education alone is inadequate, as it does not offer a supportive component to address psychological well-being and coping skills in maintaining adherence to BCRL self-management (Armer, Brooks, & Stewart, 2011). In a cohort of 34 patients with BCRL, Blaise et al. (2017) reported statistically significant improvement in visual analog scale scores of the ability to cope with lymphedema with the addition of a therapeutic education program that included a supportive component of 1:1 and group consultations and patient selection of two workshops. Ridner et al. (2016) reported focus group findings ($N = 21$) that identified the following central themes: (a) lack of social support, (b) lack of resources for self-care activities, and (c) self-advocacy by default. Subthemes from the study were indicative of the perceived marginalization that occurs with BCRL. Patients' cognitive representations of lymphedema risk and severity play a large role in determining health-related behaviors (Leventhal, Phillips, & Burns, 2016). Positive perceptions of self-efficacy, the belief that he or she can affect a situation or condition, and self-regulation, the ability to control emotion, behavior, and distractions that may interfere with preset goals to control any given health threat, such as BCRL (Leventhal, Leventhal, & Breland, 2011; Leventhal et al., 2016), are integral to adherence of self-management regimens to reduce risk and manage BCRL symptoms (Sherman, Miller, Roussi, & Taylor, 2015). More information is needed to understand patients' experiences and perceptions of education and support in coping with the barriers they face with self-management of BCRL.

Purpose

The purpose of two qualitative studies was to further explore patient perceptions of barriers to self-management of BCRL and gain insight to patient perceptions of BCRL education and support, answering the following research questions:

Research Question 1: What are the perceived barriers associated with BCRL management for female breast cancer survivors with BCRL?

Research Question 2: What perceptions do female breast cancer survivors diagnosed with BCRL have in relation to BCRL educational content, practices, and support?

Method

Design

Descriptive qualitative studies were conducted using nonprobability purposive sampling to recruit two groups of participants. The first study was conducted as a focus group, with a subsequent study conducted a year later using mailed surveys. The studies were approved by the University Institutional Review Board. The focus group session questions guided participant discussion relevant to barriers to self-management of BCRL. The focus group semi-structured interview guide can be found in Online Supplementary Figure 1. Although the focus group data were consistent with researcher experience and a review of contemporary literature regarding barriers to BCRL self-management, a gap in the literature was identified relevant to patient experiences and perceptions regarding education and support; therefore, the survey was developed to strengthen and provide more meaningful data. The survey was developed and reviewed by two researchers for content validity. Questions were open-ended, requiring narrative answers that focused on experiences and perceptions relevant to BCRL education and support throughout survivorship. The survey can be found in Online Supplementary Figure 2. The aims that guided the study were to (a) identify barriers to BCRL self-management and (b) to explore patient perceptions of BCRL education and support. Sample sizes of six to 10 participants for each study group were based on expert recommendations (Richards & Morse, 2013). Supplementary data for this article are available online.

Participants

Participants in both study groups were female breast cancer survivors who (a) completed surgical and/or radiation therapy for breast cancer treatment, (b) had medically diagnosed BCRL (self-report) and a prescribed self-management regimen by a trained therapist, and (c) had no history of lymphedema prior to breast cancer diagnosis. Summary statistics identified 20 (95.2%) participants were White (non-Hispanic) and one (4.76%) as African American. The mean age of the participants was 66.76 years, and all had at

least a high school education. In addition, participants reported a mean of 9.38 years since breast cancer diagnosis and a mean of 7.19 years since lymphedema diagnosis. Combined group definitive breast cancer treatment characteristics indicated 17 (80.9%) participants had undergone mastectomy, four (19.1%) lumpectomy, 21 (100%) sentinel lymph node dissection (SLND) and/or ALND, 18 (85.7%) chemotherapy, and 13 (61.9%) had received radiation therapy.

Focus Group Procedure

A telephone script was used for potential participants which described the purpose and expected outcomes of the study. Approximately 50 of 350 breast cancer survivors who were currently participating in survivorship studies at a university lymphedema research laboratory who agreed to be contacted about future studies were screened, at which point recruitment goals were achieved. Potential participants from a community breast cancer support group were also invited. Participants were given date, location, and time of the focus group meeting; made aware that the focus group interviews would be audio-recorded; and that the de-identified data would be used in developing an interactive theater script about lymphedema for a planned randomized intervention study.

The focus group was held at a midwestern United States university in a private, quiet conference room without risk of interruption and moderated by the first and second authors, both experienced in qualitative research. The moderators were not involved in the clinical care of the focus group participants; however, the moderators had previous contact with recruitment to other clinical studies relevant to breast cancer and lymphedema research. The session began with introductions by first name, a review of the voluntary nature of the study and its purpose, as well as a discussion of the ground rules for the session. Each participant completed a demographic form which was de-identified with a numerical code. An interview guide with semistructured questions was used to facilitate discussion. The guide was checked for content validity by two researchers prior to use. The focus group was audio-recorded using two digital recorders and a multi-directional tabletop microphone. Once the audio recordings were verified, one audio-recording was erased. Two trained research assistants supervised the recording equipment and recorded field notes. The session lasted for 2 hr, at which time data saturation was achieved. Focus group discussion encompassed topics specific to barriers to BCRL self-management; physiological, psychological, and psychosocial issues, including struggles with patient advocacy; self-efficacy; and self-regulation. At the conclusion of the focus group session,

participants received a modest gift card in recognition of their participation and time.

Survey Procedure

Surveys ($N = 15$) were mailed to participants' homes with a prepaid, self-addressed return envelope. The survey questions identified participant perceptions relative to (a) how, when, and by whom participants were told they might develop BCRL; (b) ways that educational information and support/resources were given and by whom; (c) how effective educational materials were for learning and in maintaining self-management regimens; (d) types of self-management modalities used; (e) problematic elements of self-management; (f) best ways to provide education and support in helping to maintain self-management regimens; (g) how support has been continued throughout survivorship; and (h) participant feelings about differences in QOL compared with breast cancer survivors without BCRL. All participants who agreed to complete a survey received a telephone call to notify them what date the surveys mailed. Twelve surveys were returned. Survey participants also received a modest gift card in recognition for their participation and time.

Results

Analysis

Descriptive statistics were used to analyze the demographic variables using SAS version 9 software (SAS Institute Inc., Cary, NC, USA) for both study groups. Mean and standard deviation were computed for continuous variables, and frequency and relative frequency were computed for categorical values. The focus group recording was transcribed verbatim by a trained research assistant, followed by a review for accuracy and corrections by the first author. A thematic line-by-line inductive content analysis of the data using Corbin and Strauss's (2008) coding canon for Grounded Theory was conducted for the focus group data, including analytic memos with subsequent assembling of central themes and subthemes. Agreement on independently generated codes, themes, and subthemes was achieved by triangulation with two other researchers.

Survey responses were categorically grouped according to item content, followed by thematic derivation and summarization using Dedoose version 6.1.18 (2015) software (SocioCultural Research Consultants, LLC, Los Angeles, CA, USA). Responses were then quantified using percentages.

Focus Group

In reference to the research question identifying barriers to self-management breast cancer survivors with lymphedema, three central themes were identified including: (1) the lack of BCRL patient education provided by health care providers, (2) lack of understanding by others, and (3) decreased self-efficacy. Subthemes under lack of BCRL education were (a) timing and volume of information; and (b) minimalization of BCRL education and inaccurate information from health care providers. Subthemes under lack of understanding by others included (a) feelings of marginalization and (b) non-therapeutic communication. Decreased self-efficacy subthemes included (a) treatment burden and (b) lack of follow-up support.

Theme 1: Lack of BCRL Patient Education Provided by Health Care Providers

Seven of nine participants (78%) voiced the need for better methods of communicating the risk of BCRL at the time of breast cancer diagnosis. None of the participants were aware of risk-reducing activities, except to avoid constriction with blood pressure cuffs, IV infusions, and blood draws on the side of their breast cancer treatment. As one participant shared recommendations she had received about lymphedema risk and treatment, another participant stated, “I didn’t get that memo.” The other participants stated, “We didn’t get that memo!” Another participant expressed, “No recollection of being told about lymphedema” and “. . . I think I was well-informed of the cancer itself and treatment, but not about lymphedema.”

Subtheme: Ill-timed and too much information. Participants voiced a need to know about lymphedema at the time of breast cancer diagnosis, but seemed to want it at a different time than when given breast cancer treatment information. The need for information was more pertinent for the immediate need, such as breast cancer surgery. The overwhelming shock of the cancer diagnosis allowed little ability to grasp new information other than what was needed immediately for cancer treatment. Two participants felt baseline arm measures at the preoperative visit was a good time to discuss the risk of BCRL. Examples from participants related to the amount of information were expressed as follows: “You get so much stuff at once”; “. . . I just really didn’t know about lymphedema and I probably had literature with all the stuff, but you’re overwhelmed. I didn’t read everything”; and “. . . They handed me all kinds of stuff and then I have stack, a literal stack of papers, binders to put stuff in, just hoarding . . .”

Subtheme: Minimalization of BCRL education and inaccurate information from health care providers. With the exception of lymphedema therapists, all the participants voiced the need for improved health care provider interest and accuracy of information related to BCRL, given the perceived minimization of the condition. Five of nine (56%) participants were told “not to worry about it.” The following participant statements also gave insight into how influential communication can be on the patient–provider relationship. Participant statement examples included “Yeah, and if it’s not related to your oncologist, to your cancer, then the oncologist says, ‘You need to see your primary physician. I don’t deal with that.’ That’s aggravating. They need to work together”; “. . . I said something about baseline and they said, ‘Oh, we only took a couple [lymph nodes], just a few, you don’t have to worry about it’ . . .”; and “I think the doctor should talk to you about it.” The participants also agreed that education about BCRL incidence was neglected. One participant stated, “I think being 5 years out, I thought I was past it.” Another said, “. . . That’s what I tell everybody; it can happen at any time because mine is 5 years out!” Two participants have taken it upon themselves to educate other women about lymphedema. One participant is a volunteer at a local hospital, and another has started an online support group. Ridner et al. (2016) reported qualitative results of 21 breast cancer survivors with BCRL in which “self-advocacy by default” was identified as a theme. The authors believe this to be true in this study with added concerns that forced self-advocacy is an unintended outcome that risks inaccuracy of medical information and an incomplete knowledge base of resources. A health care provider’s lack of interest and communication may be indicative of a knowledge deficit about BCRL. Based on an international, multidisciplinary panel of experts, the American Society of Breast Surgeons (ASBrS) published recommendations that clinicians should establish prospective surveillance of all breast cancer patients, including those treated with conservation surgery with SLNB and/or ALND (McLaughlin et al., 2017). The comments shared by the study participants make it evident that BCRL knowledge is insufficient, especially regarding the number of lymph nodes removed and follow-up instruction. Conclusions of a cross-sectional survey of 175 breast cancer survivors relative to arm care after breast cancer surgery indicated that (a) health care professionals’ advice did not meet the needs and expectations of the participants and (b) health care professionals could do better by providing accurate advice relevant to their surgery (Lee, Kilbreath, Sullivan, Refshauge, & Beith, 2010). In addition to lack of interest, health care providers may need additional education regarding BCRL.

Theme 2: Lack of Understanding by Others

Participants in the study commented on the desire for people to understand lymphedema. Psychological distress relative to encounters with the public, family, and friends were voiced as commonplace. One participant commented, “. . . People that you know will comment and ask, ‘How are you doing today?’ or ‘Is it better today?’ It gets a little embarrassing; you get tired of answering . . .” Another participant stated, “It’s uncomfortable and you get a lot of strange questions.”

Subtheme: Feelings of marginalization. There is inadequate knowledge about BCRL as a chronic condition which tends to elicit irrelevant questions such as “What’s wrong with your arm?” or “Did you get burned?” Participants discussed how insignificant they were made to feel as a result of insincerity by others. Comments were shared including “Then they say, ‘How are you doing?’ and then you wonder, ‘Do you really care?’” and “. . . How can I talk about lymphedema? So much negativism associated with the fact . . . You know, they just start looking at you.” Although a source of frustration with feelings of marginalization, three (33%) participants used public encounters as a teaching opportunity. One participant stated, “And I figure if somebody can learn from me wearing a sleeve and asking questions, maybe they’ll do something to prevent it.” Another participant viewed questions about their lymphedema as a positive act of caring, stating, “. . . It’s certainly nice to have people interested in you.”

Subtheme: Nontherapeutic communication. There was unanimous agreement on the importance of caring communication that takes place in facilitating collaboration between patients and health care providers; however, communication is also important within patients’ network of family and friends. The participants unanimously agreed that a trusting relationship and respect for confidentiality is important when discussing illness or chronic conditions. One participant stated, “I didn’t even talk about it with my mother-in-law . . . she never even knew I had breast cancer, but she was the type of person that called everybody and told them everything.” An additional aspect of communication may be influenced on the age of family members and cultural differences relative to serious conditions. One participant shared, “I was over at my mom and dad’s (85 and 89 years of age). [When I spoke of my cancer and lymphedema], my Dad said, ‘Shut up! Don’t talk about it, you’re gonna bring it back!’” This comment indicated that the stigma of cancer and chronic conditions can be a hindrance to communication and support.

Theme 3: Decreased Self-Efficacy

In addition to education, confidence in one's effectiveness to self-manage BCRL is a significant contributor to successful treatment. Participants agreed with the concept of self-efficacy; however, most felt that they could do better in adherence to self-management regimens. One participant stated, "I give myself a B. I could do manual lymphatic drainage and I could wear my sleeve more when I'm gardening." Another agreed saying, "I think I've been lazy . . ."

Subtheme: Treatment burden. The average number of treatment modalities used by the participants for BCRL management was three, of which wearing a compression sleeve and glove was the most common. Participants agreed that the most common barrier to treatment was the lack of time, weather, physiological symptoms, and lack of help. One participant stated, "I don't want to, because I think I'm not doing anything." Additional comments included "I think just that uncomfortableness of the garment. I don't really care for the way it feels"; "Well, they're [sleeve] hot"; "Yeah, it's hot"; "I don't always wear my sleeve when I'm gardening because it's hot out"; "My hand swells up with my glove on or off"; and "I can't do it."

Subtheme: Lack of follow-up support. There is a need for ongoing support throughout survivorship. Patients with BCRL are responsible for self-management after intensive therapy with a lymphedema therapist, but there is no protocol beyond initial treatment. One participant stated, "I don't do the manual lymphatic drainage thing. I did it for a long time, then I just kind of quit that." Follow-up for reevaluation of BCRL with arm measures and appropriate fitting of compression garments should be implemented at mutually agreed-upon intervals. Participants agreed that a prospective model of surveillance would be beneficial. One participant stated, "I think one thing that would have kept me on the program more is if I had follow-ups."

Surveys

The second research question addresses perceptions of BCRL educational content, practices, and support experienced by female breast cancer survivors diagnosed with BCRL. Of 15 surveys mailed, 12 (80%) were returned. Item responses indicated that the best way to provide both education and support was through interaction with others (81% and 77%, respectively). As the most common method used by health care providers is through printed information, this study identified a disconnect between what health care providers are doing and what the participants felt was most helpful. Education about BCRL was not

consistently provided, and 53% of the participants defined education as a “referral when symptoms emerged.” For the women who received education, it was provided at the time of BCRL diagnosis, thus denying them education regarding BCRL risk-reducing activities and precautions at the time of breast cancer diagnosis. Support was defined as “prescriptions” and “referrals” by 51% of the participants; therefore, it is unclear whether patients were exposed to support other than medical treatment. Consistent with contemporary literature, participants responded that decreased QOL was more prevalent in women with lymphedema compared with those without.

Discussion

Focus group interviews and responses from mailed surveys identified issues that are critical to successfully managing BCRL and in providing effective educative-supportive programs throughout survivorship. The lack of BCRL education, lack of understanding by others, and decreased self-efficacy may contribute to unsuccessful BCRL management, development of serious complications, participants’ withdrawal from BCRL information-seeking behaviors, and decreased self-efficacy. Self-management is only effective if it is performed, and follow-up support is critical to helping women who struggle with BCRL on a daily basis (Armer et al., 2008; Brown et al., 2014; Cal & Bahar, 2016; Fu et al., 2013; Ridner et al., 2012; Ridner et al., 2016; Rosedale & Fu, 2010). In addition, there are few alternative interventions used to provide education other than printed information and none that are currently designed to impact adherence (Ostby & Armer, 2015). Participant consensus indicated that follow-up with health care providers and education about BCRL treatment and risk-reduction activities would have facilitated earlier intervention for their lymphedema. These perceptions validate studies reporting that women who are more knowledgeable and confident of their effectiveness in BCRL self-management are more likely to maintain adherence (Fu, Chen, Haber, Guth, & Axelrod, 2010; Sherman & Koelmeyer, 2013; Sherman et al., 2015).

The majority of survey participants indicated that BCRL education was not provided until they developed BCRL. One major finding in the study demonstrated that 81% of the survey participants indicated that interaction with others worked best for learning about BCRL and 77% of participants preferred interaction with others as the best means for providing support. Given that 51% of participants defined support as “prescriptions” and “referrals,” this suggests that participants may not be able to identify preferred types of support because they are unaware of options and need help to understand and select the types of education and support that will best fit their needs.

Suboptimal BCRL self-management adherence rates may be directly or indirectly related to the lack of interactive patient-centered programs that provide education and support throughout survivorship. Nurse researchers can be instrumental in conducting patient-centered research that will provide evidence-based alternatives to education and support for chronic treatment-related conditions, such as BCRL.

These studies led to the following conclusions that warrant further study: (a) Patients are voicing the need for accurate information from health care providers prior to definitive treatment for breast cancer, (b) a supportive component to care throughout survivorship should be included with BCRL education, (c) assessment of cognitive and emotional factors should be included in educative-supportive programs, (d) research studies are needed to further explore alternative types of education and support from which patients can choose, and (e) patient-centered interactive approaches to education may be more effective than current strategies.

Patients need to have educative-supportive options so they can choose what works best for them in coping with chronic disease and conditions such as BCRL. Findings from this study indicated that an interactive approach to education and support were the preferred methods of delivery. In addition, this study provided the preliminary work for a randomized study comparing printed information about BCRL with printed information and an interactive theater intervention, the latter using the focus group data as the basis for the interactive theater intervention script.

The homogeneity of the participants in regard to race and age was a limitation of this study. Small sample sizes prohibited generalizability; however, based on contemporary literature, experience, and Glaser and Strauss's (1967) definition of saturation, it was unlikely that adding more participants in this case would have yielded additional information or perspectives. Glaser and Strauss (1967) recommend the concept of saturation for achieving an appropriate sample size in qualitative studies.

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Supplemental Material

Supplementary material is available for this article online.

References

- Alcorso, J., Sherman, K. A., Koelmeyer, L., Mackie, H., & Boyages, J. (2016). Psychosocial factors associated with adherence for self-management behaviors in women with breast cancer-related lymphedema. *Supportive Care in Cancer, 24*, 139-146.
- American Cancer Society. (2017). *Cancer facts & figures 2017*. Retrieved from <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2017/cancer-facts-and-figures-2017.pdf>
- Armer, J. M., Brooks, C. W., & Stewart, B. R. (2011). Limitations of self-care in reducing the risk of lymphedema: Supportive-educative systems. *Nursing Science Quarterly, 24*, 57-63. doi:10.1177/0894318410389058
- Armer, J. M., Henggeler, M. H., Brooks, C. W., Zagar, E. A., Homan, S., & Stewart, B. R. (2008). The health deviation of post-breast cancer lymphedema: Symptom assessment and impact on self-care agency. *Self-Care, Dependent-Care & Nursing, 16*, 14-21.
- Armer, J. M., Hulett, J. M., Bernas, M., Ostby, P., Stewart, B. R., & Cormier, J. N. (2013). Best-practice guidelines in assessment, risk reduction, management, and surveillance for post-breast cancer lymphedema. *Current Breast Cancer Reports, 5*, 134-144. doi:10.1007/s12609-013-0105-0
- Armer, J. M., & Stewart, B. R. (2010). Post-breast cancer lymphedema: Incidence increases from 12 to 30 to 60 months. *Lymphology, 43*, 118-127.
- Bellury, L., Ellington, L., Beck, S. L., Pett, M. A., Clark, J., & Stein, K. (2013). Older breast cancer survivors: Can interaction analyses identify vulnerable subgroups? A report from the American cancer society studies of cancer survivors. *Oncology Nursing Forum, 40*, 325-336.
- Bernas, M. J., Askew, R. L., Armer, J. M., & Cormier, J. N. (2010). Lymphedema: How do we diagnose and reduce the risk of this dreaded complication of breast cancer treatment? *Current Breast Cancer Reports, 2*, 53-58. doi:10.1007/s12609-010-0009-1
- Blaise, S., Satger, B., Pernod, G., Richaud, C., Villemur, B., & Carpentier, P. H. (2017). Impact of an educational program on the quality of life of patients with

- lymphedema: A preliminary evaluation. *Journal of Vascular Surgery: Venous and Lymphatic Disorders*, 5, 715-722. doi:10.1016/j.jvsv.2017.06.004
- Boris, M., Weindorf, S., & Lasinski, B. (1997). Persistence of lymphedema reduction after noninvasive complex lymphedema therapy. *Oncology*, 11, 99-109.
- Brown, J. C., Chevile, A. L., Tchou, J. C., Harris, S. R., & Schmitz, K. H. (2014). Prescription and adherence to lymphedema self-care modalities among women with breast cancer-related lymphedema. *Supportive Care in Cancer*, 22, 135-143. doi:10.1007/s00520-013-1962-9
- Brown, J. C., Kumar, A., Chevile, A. L., Tchou, J. C., Troxel, A. B., Harris, S. R., & Schmitz, K. H. (2015). Association between lymphedema self-care adherence and lymphedema outcomes among women with breast cancer-related lymphedema. *American Journal of Physical Medicine & Rehabilitation*, 94, 288-296.
- Cal, A., & Bahar, Z. (2016). Women's barriers to prevention of lymphedema after breast surgery and home care needs: A qualitative study. *Cancer Nursing*, 39(6), 17-25. doi:10.1097/NCC.0000000000000326
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.
- Dedoose Version 6.1.18. (2015). *Web application for managing, analyzing, and presenting qualitative and mixed method research data*. Los Angeles, CA: SocioCultural Research Consultants, LLC. www.dedoose.com.
- Deng, J., Fu, M. R., Armer, J. M., Cormier, J. N., Radina, E., Thiadens, S. R., . . . Ridner, S. H. (2013). Self-reported information sources and perceived knowledge in individuals with lymphedema. *Lymphology*, 46, 173-183.
- DiSipio, T., Rye, S., Newman, B., & Hayes, S. (2013). Incidence of unilateral arm lymphoedema after breast cancer: A systematic review and meta-analysis. *The Lancet Oncology*, 14, 500-515.
- Douglass, J., Graves, P., & Gordon, S. (2016). Self-care for management of secondary lymphedema: A systematic review. *PLoS Neglected Tropical Diseases*, 10(6), 1-20. doi:10.1371/journal.pntd.0004740
- Fu, M. R., Chen, C. M., Haber, J., Guth, A. A., & Axelrod, D. (2010). The effect of providing information about lymphedema on the cognitive and symptom outcomes of breast cancer survivors. *Annals of Surgical Oncology*, 17, 1847-1853. doi:10.1245/s10434-010-0941-3
- Fu, M. R., & Kang, Y. (2013). Psychosocial impact of living with cancer-related lymphedema. *Seminars in Oncology Nursing*, 29, 50-60. doi:10.1016/j.soncn.2012.11.007
- Fu, M. R., Ridner, S. H., Hu, S. H., Stewart, B. R., Cormier, J. N., & Armer, J. M. (2013). Psychosocial impact of lymphedema: A systematic review of literature from 2004 to 2011. *Psycho-Oncology*, 22, 1466-1484. doi:10.1002/pon.3201
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Piscataway, NJ: Transaction Publishers.
- Howlander, N., Noone, A. M., Krapcho, M., Miller, D., Bishop, K., Kosary, C. L., . . . Cronin, K. A. (Eds.). (2017). *SEER Cancer Statistics Review, 1975-2014*.

- Bethesda, MD: National Cancer Institute. Retrieved from https://seer.cancer.gov/csr/1975_2014/
- International Society of Lymphology. (2016). The diagnosis and treatment of peripheral lymphedema: 2016 Consensus document of the International Society of Lymphology. *Lymphology*, *49*, 170-184.
- Kwan, M. L., Shen, L., Munneke, J. R., Tam, E. K., Partee, P. N., André, M., . . . Thiadens, S. R. J. (2012). Patient awareness and knowledge of breast cancer-related lymphedema in a large, integrated health care delivery system. *Breast Cancer Research and Treatment*, *135*, 591-602. doi:10.1007/s10549-012-2199-x
- Lasinski, B. B. (2013). Complete decongestive therapy for treatment of lymphedema. *Seminars in Oncology Nursing*, *29*, 20-27. doi:10.1016/j.soncn.2012.11.004
- Lasinski, B. B., McKillip Thrift, K., Squire, D., Austin, M. K., Smith, K. M., Wanchai, A., . . . Armer, J. M. (2012). A systematic review of the evidence for complete decongestive therapy in the treatment of lymphedema from 2004 to 2011. *PM&R*, *4*, 580-601. doi:10.1016/j.pmrj.2012.05.003
- Lee, T. S., Kilbreath, S. L., Sullivan, G., Refshauge, K. M., & Beith, J. M. (2010). Patient perceptions of arm care and exercise advice after breast cancer surgery. *Oncology Nursing Forum*, *37*, 85-91. doi:10.1188/10.ONF.85-91
- Leventhal, H., Leventhal, E. A., & Breland, J. Y. (2011). Cognitive science speaks to the "common-sense" of chronic illness management. *Annals of Behavioral Medicine*, *41*, 152-163. doi:10.1007/s12160-010-9246-9
- Leventhal, H., Phillips, L. A., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): A dynamic framework for understanding illness self-management. *Journal of Behavioral Medicine*, *39*, 935-946.
- McLaughlin, S. A., Staley, A. C., Vicini, F., Thiruchelvam, P., Hutchison, N. A., Mendez, J., . . . Feldman, S. M. (2017). Considerations for clinicians in the diagnosis, prevention, and treatment of breast cancer-related lymphedema: Recommendations from a multidisciplinary expert ASBrS panel. *Annals of Surgical Oncology*, *24*, 2818-2826.
- Miller, C. L., Specht, M. C., Skolny, M. N., Horick, N., Jammallo, L. S., O'Toole, J., . . . Taghian, A. G. (2014). Risk of lymphedema after mastectomy: Potential benefit of applying ACOSOG Z0011 protocol to mastectomy patients. *Breast Cancer Research and Treatment*, *144*, 71-77.
- National Lymphedema Network. (n.d.). *NLN position paper: The diagnosis and treatment of lymphedema*. Retrieved from <https://www.lymphnet.org/resources/nln-position-paper-the-diagnosis-and-treatment-of-lymphedema>
- Ostby, P. L., & Armer, J. M. (2015). Complexities of adherence and post-cancer lymphedema management. *Journal of Personalized Medicine*, *5*, 370-388. doi:10.3390/jpm5040370
- Ostby, P. L., Armer, J. M., Dale, P. S., Van Loo, M. J., Wilbanks, C. L., & Stewart, B. R. (2014). Surveillance recommendations in reducing risk of and optimally managing breast cancer-related lymphedema. *Journal of Personalized Medicine*, *4*, 424-447. doi:10.3390/jpm4030424

- Richards, L., & Morse, J. M. (2013). Making data. In V. Knight & M. Granger (Eds.), *Readme first for a user's guide to qualitative methods* (3rd ed., pp. 119-147). Los Angeles, CA: Sage.
- Ridner, S. H., & Dietrich, M. S. (2008). Self-reported comorbid conditions and medication usage in breast cancer survivors with and without lymphedema. *Oncology Nursing Forum*, *35*, 57-63.
- Ridner, S. H., Dietrich, M. S., & Kidd, N. (2011). Breast cancer treatment-related lymphedema self-care: Education, practices, symptoms, and quality of life. *Supportive Care in Cancer*, *19*, 631-637. doi:10.1007/s00520-010-0870-5
- Ridner, S. H., Fu, M. R., Wanchai, A., Stewart, B. R., Armer, J. M., & Cormier, J. N. (2012). Self-management of lymphedema: A systematic review of the literature from 2004 to 2011. *Nursing Research*, *61*, 291-299.
- Ridner, S. H., Rhoten, B. A., Radina, M. E., Adair, M., Bush-Foster, S., & Sinclair, V. (2016). Breast cancer survivors' perspectives of critical lymphedema self-care support needs. *Supportive Care in Cancer*, *24*, 2743-2750. doi:10.1007/s00520-016-3089-2
- Rosedale, M., & Fu, M. R. (2010). Confronting the unexpected: Temporal, situational, and attributive dimensions of distressing symptom experience for breast cancer survivors. *Oncology Nursing Forum*, *37*, E28-E33. doi:10.1188/10.ONF.E28-E33
- Sherman, K. A., & Koelmeyer, L. (2013). Psychosocial predictors of adherence to lymphedema risk minimization guidelines among women with breast cancer. *Psycho-Oncology*, *22*, 1120-1126. doi:10.1002/pon.3111
- Sherman, K. A., Miller, S. M., Roussi, P., & Taylor, A. (2015). Factors predicting adherence to risk management behaviors of women at increased risk for developing lymphedema. *Supportive Care in Cancer*, *23*, 61-69. doi:10.1007/s00520-014-2321-1
- Stuiver, M. M., Ten Tusscher, M. R., & McNeely, M. L. (2017). Which are the best conservative interventions for lymphoedema after breast cancer surgery? *British Medical Journal*, *357*, Article j2330.
- Tam, E. K., Shen, L., Munneke, J. R., Ackerson, L. M., Partee, P. N., Somkin, C. P., . . . Kwan, M. L. (2012). Clinician awareness and knowledge of breast cancer-related lymphedema in a large, integrated health care delivery setting. *Breast Cancer Research and Treatment*, *131*, 1029-1038. doi:10.1007/s10549-011-1829-z