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ORIGINAL ARTICLE

Breast cancer survivors' perspectives of critical lymphedema self-care support needs

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Abstract
Purpose To solicit breast cancer survivors' perspectives on the variety of issues they face related to lymphedema self-care and identify support needs perceived as critical for managing their chronic medical condition.
Methods Twenty-one breast cancer survivors with lymphedema participated in audio-recorded focus groups about barriers and facilitators of self-care. Transcripts were analyzed using ATLAS.ti software by two coders. Triangulation of findings provided for refinement and category confirmation.
Results Themes identified included lack of social support, lack of resources for self-care activities, and self-advocacy by default. Lack of social support subthemes were feeling misunderstood, minimization of needs, and feeling criticized. Lack of resources for self-care activities subthemes were lack of both tangible self-care support and self-care supplies. Self-advocacy by default subthemes were the need to proactively manage lymphedema complications, the need to educate health-care workers, and feeling marginalized by the health-care system.
Conclusions Lack of support and the failure of others to recognize lymphedema as a chronic condition set this patient population apart from other patients with chronic diseases and decreases the amount of help needed to manage the condition.

Keywords Lymphedema · Breast cancer · Self-care · Barriers · Oncology

Introduction

Breast cancer and breast cancer treatment may damage the lymphatic system, creating an environment in which lymph fluid stasis and lymphedema in an affected arm and/or truncal area can develop [1, 2]. Lymphedema onset is a stressful, potentially life-altering event that can occur during treatment or years later [3, 4]. Once lymphedema develops, it becomes a progressive medical condition that presents psychological and physical challenges to approximately 40 % of the 2.3 million breast cancer survivors in the USA [5–7]. Multiple studies support that, in addition to swelling, altered arm sensations, pain, decreased function, fatigue, psychological distress, loss of confidence in body image, and reduction of activity also occur [3–5, 8–11].

There is no surgical or medical cure for breast cancer-related lymphedema. Lymphedema may progress through three swelling stages ranging from soft pitting swelling to very thick skin with large skin folds [12, 13]. A rehabilitation model guides the current standard treatment and reimbursement rates. Treatment typically consists of two-phase complete decongestive therapy (CDT) [8]. Phase I is administered by a trained individual who provides manual lymphatic drainage (MLD), applies compression garments or bandages, and teaches meticulous skincare techniques and arm exercises to stimulate movement of lymph. Phase II of CDT is self-care and generally includes wearing a compression garment and/or self-bandaging, conducting self-MLD, and completing skincare and arm exercises. CDT does not return the lymphatic system to normal function, and swelling exacerbations are common. Lifelong self-care is required to

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slow the progression of lymphedema and reduce negative health outcomes. Lymphedema self-care practices target swelling and skin; however, self-care should also address associated physical and psychosocial symptoms. Likewise, "as needed" caregiver and medical support to manage the condition also seem logical.

Previous studies have reported as many as 50 % of those affected do not adhere to prescribed self-care [3, 14–16]. Therefore, many experience unmanaged symptoms and a less than desireable quality of life. Published works suggest possible explanations for the poor adherence rate. Standard lymphedema self-care activities are time-consuming, burdensome, and never-ending [17]. There is often lack of access to certified lymphedema therapists who provide education and support for self-care. Reimbursement for education and routine lymphedema check-ups are non-existent, thus setting this chronic medical condition apart from other chronic medical conditions such as diabetes. Specifically, diabetes is recognized by both the lay public and health professionals as a chronic medical condition for which standard care includes daily self-care activities, "as needed" caregiver assistance, and medical support to manage not only blood glucose level but also associated symptoms such as neuropathy and changes in vision [18]. Lymphedema does not have such recognition. More information is needed to better ascertain the salient issues perceived by patients that impact lymphedema self-care. Patient-identified issues need to be addressed if symptom burden and quality of life are to improve. The purpose of this study was to solicit breast cancer survivors' perspectives on the issues they face related to self-care and to identify support needs perceived as critical for managing their chronic medical condition.

Materials and methods

Study setting and participants

The study was conducted at Vanderbilt University School of Nursing in Nashville, TN. Following Institutional Review Board approval, participants were recruited from an existing patient registry. Participants had to be age 18 or older, have stage II lymphedema subsequent to breast cancer treatment, live within driving distance of the study site (35 miles), and be able to see and read documents in English. Individuals were excluded if they were undergoing chemotherapy or radiation or were in hospice. Registry participants were contacted by phone and, if interested, were screened using stated eligibility criteria. Once screened, they were mailed a consent form and a list of the focus group questions that were developed based upon social cognitive theory (Table 1). Each participant was assigned to a focus group based on her availability. Participants brought their signed informed consent form to the focus group meeting.

Table 1 Focus group questions

1. What can supportive others do to encourage and help you with managing your lymphedema?
2. What would help you the most with needs related to daily massage and wrappings?
3. Have there been ways that your friends/family have tried to help you that have not been helpful?
   If so, what were these behaviors?
4. How do you deal with feeling dependent on others for help?
5. How do you ask others to help you when needed?

Design

We enrolled participants from January 2013 to March 2013. We used a qualitative, descriptive design. Three 90-min focus groups were held, led by the primary investigator, co-investigator, and a trained registered nurse. Each group began with an introduction stating the guidelines regarding use of first names only, confidentiality of content, a reminder that the group was being audio taped, and what to do if they became upset. Participants completed demographic and breast cancer treatment information forms prior to focus group discussions. Discussion began with the same neutral open-ended question: "What can supportive others (people from whom you would expect support) do to encourage and help you manage your lymphedema?" Follow-up questions were based upon the group's response to the first question and other questions, such as "How do you ask others for help when you need it?" All focus groups were audio recorded.

Data analysis

Recordings were transcribed verbatim. Names were stripped and a study identification number was assigned to each participant. A trained research assistant ensured transcription accuracy prior to analysis by reading the complete transcriptions, comparing them to the audio recordings, and correcting discrepancies. Statements from all participants were included in the analysis. Transcript data were analyzed using traditional content analysis. Two trained, independent coders used ATLAS.ti software to code each transcript. This process involved line-by-line coding of the transcripts for repeated words and phrases. This initial coding was clustered into groups representing broader categories of codes. After separately coding the transcripts, the coders met to discuss their findings. Coder triangulations provided further refinement and confirmation of themes and subthemes. A third, non-biased outside consultant independently reviewed the transcripts and codes, resulting in additional confirmation of themes and subthemes. Participants were included in each theme or subtheme if their statements were coded as part of each theme or subtheme using the software program. Representative quotes from each focus group and theme are included in this manuscript. Descriptive statistics were used to summarize participants' demographic and breast cancer treatment characteristics.

Results

Participant characteristics

Table 2 summarizes participant demographic characteristics ($N = 21$). Participants were females and ranged in age from 41 to 64 years. The majority identified as White ($n = 14$, 67 %) with a 33 % minority representation [American Indian ($n = 1$), Asian ($n = 2$), and Black ($n = 4$)]. Most reported being married or partnered ($n = 14$, 66.7 %) and having private insurance ($n = 17$, 81 %).

Breast cancer treatment characteristics are described in Table 3. Most had received chemotherapy, radiation, and some type of surgery ($n = 15$, 71 %). The most common surgical procedure was modified radical mastectomy ($n = 9$, 43 %). The majority were post-menopausal ($n = 18$, 86 %). All had stage II lymphedema. Table 4 summarizes lymphedema location and current treatment strategies.

Patterns operating in focus group data

Three overarching themes were identified: lack of social support, lack of resources for self-care activities, and self-advocacy by default. Each theme had subthemes. Lack of social support subthemes were feeling misunderstood, minimization of needs, and feeling criticized. The theme lack of resources for self-care activities had two subthemes: lack of tangible self-care support and lack of self-care supplies. Self-advocacy by default had three subthemes: the need to proactively plan to manage lymphedema complications, the need to educate health-care providers, and feeling marginalized by the health-care system. Themes and subthemes are presented in the following sections.

Theme 1: lack of social support

This theme was present in statements made by 7 of the 21 participants (33 %). Participants gave examples of negative verbal and nonverbal reactions from others. Several described insensitive comments made to them and strangers staring at their arms.

Table 2 Demographic characteristics ($N = 21$)

Characteristics	Values
Age, mean, SD	53.8, 6.8
IQR 25–75	47.5–59.5
min, max	41, 64
Race	*n* (%)
White	14 (66.7)
Black	4 (19.0)
Asian	2 (9.5)
American Indian	1 (4.8)
Ethnicity	
Non-Hispanic	20 (95.2)
Did not care to respond	1 (4.8)
National origin	
USA	13 (61.9)
Bangladesh	1 (4.8)
Did not care to respond	7 (33.3)
Marital status	
Single	7 (33.3)
Married or partnered	14 (66.7)
Employment status	
Full time	12 (57.1)
Part time	1 (4.8)
Others	8 (38.1)
Area of residence	
City	14 (66.7)
Country	4 (19.0)
Others	3 (14.3)
Primary insurance coverage	
Private insurance	17 (81.0)
Government insurance	2 (9.5)
Others	2 (9.5)
Highest grade of education completed	
High school graduate	3 (14.3)
Some college	8 (38.1)
College graduate	10 (47.6)
Yearly household income	
≤60,000	9 (42.9)
≥60,000	10 (47.6)
Did not care to respond	2 (9.5)

Subtheme: feeling misunderstood

Participants expressed being frustrated that others did not understand that lymphedema is a chronic medical condition requiring complex treatment. One participant stated, "People just don't understand."

Another agreed saying, "Yeah, and people around you look like, 'Isn't it done? You're wearing that thing again?' People that don't know: 'Well if it's fluid, can't they just drain that off?"

Table 3 Breast cancer treatment ($N = 21$)

Characteristics	Number (%)
Chemotherapy	
Some	20 (95.2)
None	1 (4.8)
Surgery type	
Lumpectomy	8 (38.1)
Modified radical mastectomy	9 (42.8)
Radical mastectomy	3 (14.3)
Missing response	1 (4.8)
Reconstruction	
None	8 (38.1)
Immediate	8 (38.1)
Delayed	4 (19.0)
Missing response	1 (4.8)
Radiation therapy	
Some	16 (76.2)
None	5 (23.8)
Complete treatment received	
Surgery + radiation	1 (4.8)
Surgery + chemo	5 (23.8)
Surgery + radiation + chemo	15 (71.4)
Hormone inhibitors	
Yes	13 (61.9)
No	8 (38.1)
Menstrual status	
Pre-menopausal	3 (14.3)
Post-menopausal	18 (85.7)

This frustration led to feelings of being misunderstood by others and unsupported in their struggle with lymphedema. Participants with long-term lymphedema had seen little improvement in understanding of others during the years they had the condition.

Table 4 Lymphedema location and current treatment strategies ($n = 20^a$)

Location	Number (%)
Right	12 (60)
Left	7 (35)
Bilateral	1 (5)
Treatment type (current)	
None	3 (15)
Compression sleeve	3 (15)
Compression sleeve + glove	1 (5)
Complete decongestive therapy	1 (5)
Others	12 (60)

[a] One participant did not respond

Subtheme: minimization of needs

Participants felt their lymphedema was minimized by others who invalidated them and did not help with daily tasks. As a result, they experienced a lack of emotional and social support, sensing abandonment by family and friends. Two described their perceptions of others' minimizing attitudes. One said, "I think people think, 'Oh she's just got a swollen hand; it's not a big deal." Another explained,

> "We're in a society today where we talk about sexual identity, and we talk about rapes, and we talk about trauma, and PTSD, and all these things I hear every day from folks in my office setting, but nobody talks about lymphedema."

Others described family members who minimized their need for physical assistance. One woman reported feeling unsupported with household responsibilities,

> "I wear my sleeve if I know I'm going to be out—if I'm chopping wood or bringing wood in or doing any heavy lifting or, you know, mowing the lawn—because my, my kids are grown, my husband's no help."
>
> This experience was similarly described by one who said,
>
> "But I live in a house full of guys, and when I would ask for help, they would be like, 'Now? Why do I have to do that now?'"
>
> Another woman verbalized
>
> "It'll last one time and then they're like, 'Oh…' you know. 'I hope she doesn't ask me to do that anymore.'"

Participants who described feeling that their needs were minimized believed those around them usually seemed oblivious to their chronic condition and need for assistance.

Subtheme: feeling criticized

Participants with lymphedema occasionally encountered critical remarks from others that elicited hurtful, defensive feelings. Two statements are exemplar descriptions of feeling criticized. The first described a comment in which the other person insinuated that her lymphedema condition was her fault: "They think, 'Why can't you do better? Why is your arm that swollen?' And it gets very depressing sometimes. And they will make remarks about your arm and why you can't do better with your arm." These kinds of comments made another feel the need to defend herself against others who may not be informed about lymphedema. She said,

> "When you have lymphedema, you're in a club, too, and I really feel like I need that support because I'm having to defend myself at a doctor's office. I'm having to defend myself when someone asks me why I don't have a coat."

This statement also speaks to the difficulty in finding garments that accommodate the asymmetrical size of their limbs. The feeling of being criticized was frequently mentioned as many expressed frustration when others questioned their lymphedema or how they cared for themselves.

Theme 2: lack of resources for self-care activities

This theme was present in statements made by 5 of the 21 participants (24 %). Within this theme, there were two related subthemes: lack of tangible self-care support and lack of self-care supplies.

Subtheme: lack of tangible self-care support

This first subtheme focused on participants' description of their difficulties performing self-care activities without assistance. One woman's statement reflects this:

> "Well, just having a third hand [would help]. I mean, having that third or fourth hand because when you're in therapy they do such a tremendous job—you know, you feel so good when it's done and then—and they're—and you've left, but then you're back home and you're, like, 'How in the world am I supposed to keep this up?'"

An unmarried participant who lived alone stated, "No, I do not have support. I live alone; I have no family here—I mean, I don't even have someone to help me wrap." Likewise, a married participant explained, "I don't even know if my night sleeve fits anymore. I imagine I could get it on and then have somebody wrap it up tight for me, but there's not that much support at the house either for that."

For these participants, having others around to provide a "third or fourth hand" was critical. This was also voiced by married and partnered participants.

Subtheme: lack of self-care supplies

Lymphedema self-care requires supplies such as short stretch bandages, compression sleeves, gauntlets, and devices such a compression pumps. Obtaining self-care supplies is often challenging. One participant stated, "Nobody ever says, 'Oh, do you need one?' There's never follow-up and that's the way it's been, all the years.'" Another participant expressed irritation about not knowing where to find the best information and supplies. "There is no centralized place to get information. There's no centralized place to get sleeves. It's all hearsay." Rather than having a clear sense of direction on how to get the supplies they need, these participants often relied on word of mouth from others.

Theme 3: self-advocacy by default

Statements related to this theme were made by 8 of the 21 participants (38 %). They described the need for self-advocacy in terms of planning for emergencies related to their lymphedema and being proactive with health-care providers. Within this theme of self-advocacy, there were three related subthemes: need to proactively plan to manage lymphedema complications, need to educate health-care providers, and feeling marginalized by the health-care system.

Subtheme: need to proactively plan to manage lymphedema complications

This subtheme encompasses the ways in which participants prepared for emergencies and self-care, if health-care workers were not available. They focused on having medications to deal with an infection (i.e., cellulitis). For example,

> "I think the most important thing that I've learned about having lymphedema is to get with your primary care doctor and find out and get some antibiotics ahead of time so that if you get it on the weekend or you can't get immediately in to see him."

One woman, who experienced arm pain, planned ahead,

> "I travel overseas….I'll take, um, like, a prescription of 10 painkillers and I take all kinds of things with me so that if I get to a place and I'm in a bad situation, I'll have whatever medicines I need."

In addition to having medications, participants planned in advance to self-advocate when under a doctor's care,

> "Whether you are in the hospital making sure—you know, sleeping with one eye open making sure they don't stick you, whether you're preparing yourself for a flight by wrapping your arm, whether you're thinking ahead of, 'Do I have my antibiotics with me today? I'm going to be away on vacation. Do I have my back-up antibiotics?' You have to pre-plan. It's not spontaneous that you just run out the door or you could run into some trouble."

There was a clear sense that having lymphedema meant learning to take care of themselves in new ways. Comments also reflected the belief that they could not depend on health-care providers to care for them in an expedient, effective manner, particularly in an emergency.

Subtheme: need to educate health-care providers

Participants described feeling the responsibility to teach various health-care providers about lymphedema. For some, this meant being constantly vigilant. One explained,

> "I have to remind medical professionals every time I go in—no blood pressures on my left arm. It's on my chart; it's on the first page, but they always go to left arm. And if you don't tell them which arm you can use, that's the one they want. They want it for the needles, they want it for the blood pressure, they want it for IVs."

Another said, "… I feel like I've actually educated my oncologist about the difficulties and about the need." This statement reflects the frustration related to the necessity of becoming the expert regarding their lymphedema.

One participant diagnosed her lymphedema after health-care providers did not accurately identify the condition.

> "So, I actually went to MRI place and did a scan, and they call me back and said, 'Oh, it's nothing.' But they didn't ever diagnose me with lymphedema; I diagnosed myself with lymphedema. Because I went online, I did research, and I found out. And, and then I went back and told my doctor that I have lymphedema."

The stress of having to teach health-care providers, who should be the experts, is a burden for patients. This lack of knowledge about lymphedema needs to be more adequately addressed in the training and continuing education of health-care workers.

Subtheme: feeling marginalized by the health-care system

The third subtheme reflects frustration about how lymphedema was marginalized, as it was not treated like other chronic diseases, particularly in hospital settings. One woman said,

> "If you're in there for a heart condition or diabetes or something else has happened, and you have some other medical condition that has nothing to do with why you're there, you're immediately flagged for nutrition, for diabetic meals. Once you've filled out your admissions or your stuff like that, it just happens and then they all make sure. But when they see you've got lymphedema and you know, 'Oh. Yeah, and your arm looks like it's three times the size it should be.' It's just, 'Oh, okay.' And I'm like, 'No, it's really not okay.'"

Participants felt frustrated that their chronic condition was not addressed like other chronic conditions. Various participants noted the general lack of awareness, resources, educational investment, and insurance coverage allocated for care of lymphedema.

Discussion

The issues identified reveal lymphedema self-care support needs for breast cancer survivors. Demographic and clinical characteristics were similar to that of other studies of breast cancer survivors with lymphedema [16, 19–21]. There are no other known studies that have examined breast cancer survivors' perspectives on the issues they face related to self-care and supportive needs perceived as critical for managing their chronic medical condition.

Lack of social support was a barrier to lymphedema self-care. Some participants did not feel they could ask family members for help with self-care, often due to the lack of understanding of their condition. Others had family members who refused to help. Critical remarks by others highlighted the lack of knowledge about the chronic nature of lymphedema and led patients to defend themselves, adding to their psychological burden. These comments may explain previous reports that breast cancer survivors with lymphedema who withdrew from social activity had high levels of distress [21]. Lack of appreciation for the limitations and difficulties imposed by lymphedema left participants feeling isolated and abandoned. These findings suggest that there is a need for public education regarding lymphedema.

Limited social and physical resources for self-care activities were barriers to lymphedema management. By not having extra hands available, the ability to perform lymphedema self-care was hampered. Difficulty obtaining lymphedema supplies was common. Participants attributed this problem to lymphedema not being managed like other chronic conditions. Points made by participants regarding lack of planned follow-up, annual assessment of arm status, or attention to self-care management suggests that a medical model may better meet the perceived needs of those with lymphedema.

Self-advocacy was a facilitator of lymphedema self-care. Participants had to advocate for appropriate treatment because providers were not aware of guidelines for their care. Participants expressed frustration from a perceived lack of protocols dealing with lymphedema during hospitalization, unlike medical treatment for other chronic conditions. This study reveals a knowledge gap among health-care providers regarding lymphedema. This is possibly related to the current rehabilitation model of care that places treatment primarily with lymphedema therapists. Frustration was reported about the failure of both laypersons and professionals to recognize that lymphedema is a *chronic* medical condition. This lack of recognition minimizes providers' ability to bill for proactive management of chronic lymphedema when volume reduction therapy is not acutely indicated. Health-care providers might be more knowledgeable about lymphedema if they were able to evaluate and treat lymphedema patients on a scheduled basis, as with other chronic diseases. This knowledge gap makes it difficult for lymphedema patients to receive consistent health care. If breast cancer survivors with lymphedema have to assume the role of educating their health-care providers, then few providers have the knowledge to guide their patients on an appropriate self-care trajectory. Furthermore, without provider guidance and support, the likelihood of the majority of survivors taking the initiative to perform lymphedema self-care is minimal.

Limitations of this study include a limited demographic makeup. The majority of individuals in this study were female, middle-aged, and post-menopausal. The findings of this study should not be generalized to other populations, especially younger survivors of breast cancer. Additionally, responses given by participants might have been slightly different if they had been interviewed individually as opposed to a group setting. Future studies that examine differences in barriers to self-care among individuals with varying racial and ethnic backgrounds will add depth to the body of knowledge surrounding this topic.

Conclusions

Reflections of participants in this study suggest that breast cancer survivors with lymphedema want recognition from both laypersons and health-care professionals that lymphedema is a chronic condition. Such recognition is needed if caregiver support is to be obtained and comprehensive medical management of this condition is to occur. The patients need more help with lymphedema self-care. Lymphedema self-care is burdensome and, in most circumstances, cannot be conducted in a vacuum. Community and health-care partners are needed to provide social and instrumental support. In order for this support to be garnered, breast cancer survivors with lymphedema have to be proactive and advocate for needed assistance.

Interventions that educate health-care professionals and patients with lymphedema about self-care regimens and the importance of adherence and self-advocacy merit investment and empirical study. Changes that promote health-care provider education and insurance support for effective medical management of this chronic condition appear to be warranted.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

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