



Hide and Seek: Body Image-Related Issues for Breast Cancer Survivors with Lymphedema

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Abstract

Although previous studies of breast cancer survivors with lymphedema have examined body image, none have examined body image as a multidimensional experience within this population. The purpose of this paper is to present focus group findings related to body image in breast cancer survivors with lymphedema. Focus groups were conducted at Vanderbilt University School of Nursing and were audio recorded and transcribed verbatim. Transcripts were coded line-by-line using ATLAS.ti software by three independent reviewers. Initial coding was clustered into categories representing broader categories of similar codes. A fourth non-biased outside consultant independently reviewed transcripts and codes. Identified themes included stigma-related concerns, and narrowed options for self-presentation. Stigma related concerns included the subthemes of uneasiness in public and avoidance, hiding both swollen parts of their body, and at times, themselves from public view. Narrowed options for self-presentation included the subthemes of limited clothing options and frustration about undesired changes in dress. Hours were spent seeking acceptable apparel. The pattern of hide and seek as a strategy to deal with body image issues has been identified as problematic. Practical assistance in locating resources and psychological support are both indicated.

Keywords: Breast Cancer; Lymphedema; Body Image; Nursing; Qualitative; Survivorship; Self-Care; Caregiver

Introduction

Lymphedema is a disfiguring condition that affects approximately 40% of breast cancer survivors [1-7]. Lymphedema can develop at any time after breast cancer treatment, remaining a threat for the rest of a survivor's life. Thus, uncertainty, not only about cancer recurrence, but also the development of lymphedema, is a lifelong companion of breast cancer survivors [8,9]. Although previous studies of breast cancer survivors with lymphedema (BCS-LE) have examined body image, none have examined body image as a multidimensional experience within this population.

Body image is a highly complex phenomenon that not only encompasses a woman's perceptions of her body, but also her physiological, psychological, and social being [10]. Body image

disturbance in breast cancer survivors is a multidimensional phenomenon that can include disfigurement, psychological distress, and impaired function. BCS-LE experience a double dose of disfigurement, as they may be initially disfigured by surgical procedures of curative intent and subsequently by lymphedema. Because lymphedema can occur years after treatment for breast cancer, these survivors may have successfully coped with initial disfigurement, only to be forced to once again muster coping mechanisms to accept their changed appearance.

Since lymphedema is a progressive condition that has frequent exacerbations, physiological factors result in a limb for which a stable size may never be achieved over the remainder of the person's life [11]. This pattern results in a continuous assault to body image. According to several studies, psychological distress is common when disfigurement occurs, and some studies have demonstrated a subsequent distressing loss of confidence in body image [12-24]. Additionally, individuals with disfigurement may perceive stigma caused by violation of social norms if not only appearance but also function is affected [25]. BCS-LE may also experience changes in day-to-day function if they cannot find acceptable clothing options for their daily lives. Appropriate clothing may impact confidence and self-esteem, particularly in individuals who have some type of disfigurement as a result of their cancer treatment.

Despite the potential for ongoing struggles with an ever changing body, there is little research in the area of body image and breast cancer-related lymphedema. One study evaluated body image change as a function of a one-year strength training program in breast cancer survivors both with (n=112) and without (n=122) lymphedema [25]. In this study, decreased body image scores were calculated from quantitative data. Low scores were present at baseline and improved by 12 months; however, no observed association between lymphedema classification and body image scores were found. This study provided valuable insight into the potential to improve body image with targeted interventions; however, it did not address in-depth issues related to body image in this population. Such issues might best be captured using qualitative methodology, which allows for participants to share their perspectives and experiences without assumption on the part of the researcher as to the concerns that will be most salient for participants. Also, these more flexible research designs place the participant and her experiences at the center of the investigation and result in data that is detailed and complex in ways that quantitative methodologies do not allow.

The purpose of this paper is to address gaps in the research literature and present findings, based on focus group data, which are related to body image in BCS-LE. These data were obtained during the development of a Web-Based Multimedia Intervention (WBMI) that addresses both self-care techniques and psychological issues that promote adherence to self-care in BCS-LE.

Methods

Sample

Following Institutional Review Board approval at Vanderbilt University in Nashville, TN, participants in an existing database of breast cancer survivors with lymphedema who had given permission to be contacted for future studies were recruited. They were asked to participate in focus groups. The participant inclusion criteria were: age

18 or older, Stage II lymphedema subsequent to breast cancer treatment as defined by the International Society of Lymphedema, live within driving distance of Nashville, TN (35 miles), and able to see and read printed documents in English. Potential participants were excluded if they did not meet these criteria; if they were undergoing chemotherapy or radiation; or if they were receiving hospice care.

Procedure

The study was discussed with interested individuals who were then screened for eligibility. Eligible participants were mailed a consent form. They also were provided with a list of the questions to be asked in the focus group (Table 1).

What can supportive others do to encourage and help you with managing your lymphedema?
What would help you the most with needs related to daily massage and wrappings?
Have there been ways that your friends/ family have tried to help you that have not been helpful? If so, what were these behaviors?
Have you discovered ways to improve the relationship with your most supportive friend/family member? If so, how?
In stretches of your life when you have been successful at doing daily self-care, how have you set and maintained goals related to this process?
Do you reward yourself in any way for consistently managing your lymphedema?
How do you deal with any discouragement you may feel about managing lymphedema?
Do you talk or write about your feelings related to lymphedema and its care? If so, how and when?
How do you deal with feeling dependent on others for help?
How do you ask others to help you when needed?
How do you deal with uncertainty related to being a breast cancer survivor with lymphedema?
How do you deal with losses or limitations in your life related to lymphedema?
Have you made any positive changes in your life due to being a breast cancer survivor with lymphedema? (changes in priorities, values, relationships, interests, altruistic pursuits)
What do you think are the most important ideas and topics to cover in our videos?
Do you have any specific suggestions about the video format?
What portion of these videos should contain vignettes of breast cancer survivors who role model effectively dealing with lymphedema?

Table 1: Focus group questions.

Participants were assigned to a focus group based on availability. Informed consent was obtained, prior to participants attending focus groups. The groups were conducted at Vanderbilt University School of Nursing in a behavioral laboratory. All focus groups were audio recorded and transcribed verbatim by an administrative assistant. Focus groups were co-led by Drs. Ridner and Sinclair. A trained registered nurse also facilitated interviews.

Data analysis

Transcribed data were read by a research assistant and compared to the audiotape prior to analysis. Any discrepancies were corrected at this time. Each transcript was analyzed line-by-line using ATLAS.ti software by three independent reviewers, and important words and phrases were identified. This initial coding was clustered into categories representing broader contexts. After separately coding the transcripts, the reviewers met to discuss their findings. Analyst triangulations provided for further elucidation and verification of categories. A fourth non-biased, outside consultant independently reviewed the transcripts and codes, resulting in additional confirmation of categories. Descriptive statistics were used to depict the sample characteristics. This paper examines the responses from a subset of participants who mentioned some aspect of body image during the focus groups.

Results

Sample

Twelve of eighteen (67%) participants spoke about some aspect of body image. The following paragraphs and tables describe this subset of participants. Descriptive characteristics of this sample (N=12) are presented in Table 2.

Age, mean, SD	52.1, 6.4
IQR 25-75	46.1-56.8
min, max	41, 61
Characteristic	Frequency (%)
Gender	
Female	12 (100)
Race	
Caucasian	8 (66.7)
African American	3 (25.0)
Asian	1 (8.3)

Marital Status	
Single	7 (58.3)
Married	5 (41.7)
Employment Status	
Employed full time	9 (75.0)
Employed part time	1 (8.3)
Unemployed	1 (8.3)
Other	1 (8.3)
Primary Insurance Coverage	
Private insurance	10 (83.3)
TennCare	1 (8.3)
HMO	1 (8.3)

Table 2: Demographic characteristics (N=12).

The average age of those participants consenting to be in the study was 52.1 years (SD=6.4 years), and participants ranged in age from 41 to 61 years of age. The average years participants had lymphedema was 7.36 (SD=5.1) and duration range was 1 to 15 years. The majority of participants were Caucasian (n=8, 66.7%); however, there was 33% minority representation. Most had private insurance coverage (n=10, 83.3%). Breast cancer disease and treatment characteristics are described in Table 3.

Characteristic	Frequency (%)
Chemotherapy	
Some	11 (91.7)
None	1 (8.3)
Surgery Type	
Lumpectomy	5 (41.7)
MRM	5 (41.7)
RM	1 (8.3)
Missing response	1 (8.3)
Reconstruction	
None	5 (41.7)
Immediate	5 (41.7)
Delayed	1 (8.3)
Missing response	1 (8.3)
Radiation Therapy	
Some	11 (91.7)
None	1 (8.3)
Complete Treatment Received	
Surgery + XRT + Chemo	10 (83.3)

Surgery + XRT	1 (8.3)
Surgery + Chemo	1 (8.3)
Menstrual Status	
Post-menopausal	9 (75.0)
Pre-menopausal	3 (25.0)

Table 3: Breast cancer treatment (N=12).

Most participants had received chemotherapy, radiation, and some type of surgery as part of their breast cancer treatment (n=10, 83.3%). A modified radical mastectomy was the most common surgical procedure experienced by participants (MRM) (n=5, 41.7%). The majority of participants were post-menopausal (n=9, 75.0%). Lymphedema description and treatment characteristics (n=11, 1 non responder) are presented in Table 4.

Location	Frequency (%)
Left	6 (50.0)
Right	5 (41.7)
Treatment Type (Initial)	
Complex Decongestive Therapy (CDT) + Compression Sleeve (CS)	4 (33.3)
CDT + CS + arm elevation (arm EL)	3 (25.0)
CDT	1 (8.3)
CDT + CS + pump	1 (8.3)
CDT + CS + pump + arm elevation	1 (8.3)
CS + arm elevation	1 (8.3)
Treatment Type (Current)	
None	2 (16.7)
CS	2 (16.7)
CDT	1 (8.3)
CDT + CS + arm exercise (arm EX) + bandaging	1 (8.3)
CDT + CS + arm EX + skin care + bandaging + pump	1 (8.3)
CS + arm EL + arm EX + skin care + bandaging	1 (8.3)
CS + arm EL + arm EX + skin care + bandaging + pump	1 (8.3)
CS + arm EL + arm EX + skin care + bandaging + pump + meds	1 (8.3)
Other	1 (8.3)

Table 4: Lymphedema characteristics (N=11, 1 non responder).

All participants had Stage II lymphedema. A substantial number of participants had lymphedema in their non-dominant left arm (n=5, 50.0%).

Qualitative Findings

Lymphedema impacts survivors' lives in a multidimensional manner. Participants described the varied effects of having lymphedema. Amy, a 50-year-old, single, Caucasian woman living with lymphedema for 6 years, offered an explanation that reflects this, "...because it is a problem and it does affect us physically, mentally, emotionally on every level – clothing, jewelry, appearance, body image, ability to do things, not do things."

Two body image-related themes emerged from the focus groups. Many participants spoke of stigma-related concerns, as well as difficulty achieving desired self-presentation due to narrowed options for self-presentation. The following sections reflect these themes along with related subthemes. Pseudonyms are used throughout the manuscript.

Theme 1: Stigma-related concerns

Stigma can be defined as a set of negative and often unfair beliefs that a society or group of people have about something [27]. In the healthcare literature, stigma often refers to a visible sign or characteristics of a disease [28]. It can also refer to a feeling that something is wrong or embarrassing in some way [29]. Participants in this study expressed many concerns about their appearance that clearly reflected perceived stigma related to their appearance. Two subthemes emerged regarding these feelings: uneasiness in public and avoidance.

Subtheme: Uneasiness in public

Some participants felt a sense of uneasiness in public because of how their arm or compression sleeve made them look. For one participant, a stranger's comments or stares could ruin an otherwise good day.

Ruth, a 62-year-old, single, Caucasian woman with lymphedema for 16 years revealed,

Because as soon as I see two people staring at my arm – when otherwise I've had a good day – or someone approaches me and asks me about my arm who's totally clueless of lymphedema and breast cancer, I brush it off real quick and just – in fact, I have even told waiters and waitresses, 'oh, I have carpal tunnel,' when they see me with my sleeve on, because I don't want to go into this thing. It's just over and over; it never ends. But pretty much, I will make a fast excuse to exit out of the conversation and then I just retreat into my own little depressed shell and sit there for a few minutes.

Another participant discussed being embarrassed when others made a joke about the appearance of her arm. Freda, a 51-year-old, single, African American woman living with lymphedema for 9 years stated,

Emotionally, when I was, first gone through therapy, it was – I hated to go out in public with this big wrapping on my arm. It was, I don't know, it was kind of embarrassing to me because people would say, "Who won the fight?" Or "what happened to your arm?" "How are things?" You know, "you beat him up." And I'm like, "what?" You know and it's like I didn't want to come out in public going, maybe to the grocery store, and initially – you were speaking of emotions – it really did, it bothered me. I did not want to do it.

One participant felt self-conscious after other travelers stared at her putting on her sleeve. Lilly, a 42-year-old, single, Asian woman living with lymphedema for 2 years offered,

It's so irritating because I travel. So, when I get on the plane, I start putting on the sleeves and, and then people kind of stare. At first they're kind of – you know, they kind of get scared, at first. They're thinking about, 'what's going on?' You know, after September 11th, you know, they kind of look at you twice. And so, to me, I's like – and I don't like to have attention to myself.

Ruth, a 62-year-old single Caucasian woman living with lymphedema for 16 years summed this up by saying, "I mean, the disfigurement gets to be so burdensome. Because everybody's eyes immediately fall to your hand and your arm"

Subtheme: Avoidance

Many participants were engaged in avoidant coping as a response to stigmatization. They deliberately orchestrated their lives to reduce public exposure because of their lymphedema. Avoidance interfered with participants' daily lives and also with obtaining needed lymphedema treatment.

One participant said she avoided things she used to enjoy doing. Beth, a 57-year-old, married, Caucasian woman living with lymphedema for 9 years said,

Some days I just don't go anywhere. I get so excited about an event – because I'm an event person and, so, I have to do the things that I'm doing, so I've let go a lot of jobs and – But, um, of going to parties, it's like I'll be so excited about going and then I just can't go. There's this fear that stops me.

Another participant mentioned avoiding even going to lymphedema therapy appointments at times. Heather, a single, 44-year-old, Caucasian woman with a 3 year history of lymphedema acknowledged, "I have not gone back and probably need to – to work through the emotional issues so that I can better address the physical management and those body image issues."

This subtheme, avoidance, not only resulted in social avoidance, but in some cases also avoidance of vitally needed treatment for their lymphedema. In the former, missed opportunities for needed social support is an end result. For the later, failure to obtain treatment can lead to worsening lymphedema, and even more threats to body image.

Taken together, the two subthemes of uneasiness in public and avoidance, when present in these women, lead to changes in social interaction. In many cases, participants who were embarrassed about how their arm and compression sleeve made them feel, actually hid from others in an effort to reduce their discomfort. In this situation, they had survived life-threatening cancer, only to become near self-imposed prisoners hiding in their own homes. Some participants clearly felt a sense of uneasiness in public and many engaged in avoidant behaviors to minimize their perception of public stigma. This recurrent perception of stigmatization led to ongoing emotional distress.

Theme 2: Narrowed options for self-presentation

Participants experienced many challenges related to being able to present themselves to others in an acceptable manner. Self-presentation became an ongoing struggle, as difficulty purchasing, modifying, and wearing stylish, comfortable apparel was a common

theme among focus group participants. This theme emerged in the comments of more than half of participants who spoke about a body image-related issue. Two subthemes emerged, limited clothing resources from which to choose and undesired changes in dress. The participants described difficulties encountered while seeking clothing and jewelry that could be adapted to their asymmetrical bodies. They also described frustration about no longer being able to wear past favorite styles of clothing because of body image issues.

Subtheme: Limited clothing resources

Limited clothing options were a source of frustration for many participants, especially those with very large arms. There were no easily accessible resources or suppliers of modifiable, stylish clothing or jewelry. These participants literally could not find clothes to wear unless they were able to afford having major alterations made. This also had an inadvertent impact on family relationships, as clothing related gift giving was off the table.

Corretta, a 58-year-old married, African American woman with a history of lymphedema for 13 years indicated this by saying, "It's an annoyance when you go shopping, like to buy clothes and things."

This subtheme was also demonstrated when Jennifer, a 47-year-old, married, Caucasian woman living with lymphedema for the past 8 years said,

You have to strategically dress. Because you've got to make sure that your arm will go in it, and if you want to cover it and if it's summer time, can you at least wear a ¾ sleeve. I mean there's so many variables that you have to look at – not just the color and 'oh, do I like it?' Is it going to work with my body anymore?

In addition, this was also indicated when Ruth, a 62-year-old Caucasian lymphedema veteran sadly explained,

My whole family knows that they cannot buy me clothes anymore for Christmas or birthdays. Because I may not can get my arm down in whatever they buy me. And they have bought me too many clothes that, I would stand there in front of them and could not get the arm down in one sleeve.

Participants disliked having to factor their lymphedema into their clothing and jewelry choices. They had to take time to learn what would work best for them and engaged in many distressing hours of unsuccessful effort to seek and find workable apparel options.

Subtheme: Frustration about undesired changes in dress

Participants also expressed frustration that having lymphedema made wearing certain types of clothing more difficult and limited their ability to wear types of clothing they had worn before lymphedema developed. They grieved the loss of the ability to wear many things they had worn in the past. One participant noted that she constantly had to think about what she wore in consideration of her lymphedema.

This was shown when Carol, a 54-year-old, married Caucasian with a 17 year history of lymphedema responded, "But it's just a part of me, and I never think about getting dressed without it."

Several participants spoke of putting off shopping for clothing. Alicia, a 48-year-old, single African American with a 5 year lymphedema history addressed this by saying, "My first time when I got started, noticing I had lymphedema, I wouldn't buy any kind of

clothes. Because it was just like, the comparison was so hard. And to this day, I still like long sleeves, it has to have a give to it. Anything that's not stretchy, I can't – I mean, I can put it on to a certain point."

Despite living with lymphedema for the past 17 years, Carol, a 54-year-old, married Caucasian woman expressed her frustration with lymphedema by saying,

Um, my frustration is with the clothes also. And day-to-day, I'm usually okay. But if I have a special occasion, if I know there are going to be pictures made, that really bothers me... my son is getting married and I'm already thinking about "what am I going to wear?" And I want it to be long sleeves. I don't want it to show. I don't want it to be – I don't want people to look at the pictures and go "let me see, does her arm really look different in that picture?" And um, somebody asked me a long time ago if I would have to wear the sleeve every day and I said, "Well I hope I'm not wearing it in my casket."

Several participants were discouraged because they could not wear their preferred type of clothing with a swollen arm. Bonnie, a 61-year-old married Caucasian with lymphedema for an unknown period discussed her situation, "I have a winter coat I dearly love and I can barely squeeze this arm in and it's really very frustrating." Lisa, a 53-year-old single Caucasian with a 5-year lymphedema history stated, "I couldn't even wear long-sleeve shirts for years." Ruth, a 62-year-old single Caucasian living with lymphedema for 16 years offered, "But, if you can imagine having an arm that is two sizes larger than your other arm and you need to go buy a dress coat. It's a disaster."

Participants were frustrated with the daily difficulties of finding, and even wearing the limited option styles of clothing while having lymphedema. The simple act of dressing each day provided reminders of change in body image and new limitations in their lives related to lymphedema.

Narrowed options for self-presentation represents a complex series of challenges that breast cancer survivors with lymphedema must face. Limited clothing resources require that valuable time be allotted to seeking out clothing that is adaptable to the differences in arm size. Additionally, even when adaptable clothing is found, it may not be appropriate for wear at certain events, e.g. cocktail parties. Thus, additional searching is required for occasion appropriate apparel.

Discussion

This study examined focus group data related to body image in breast cancer survivors with lymphedema. Sample characteristics were comparable to other studies of breast cancer survivors with lymphedema [23,30-34]. Two major themes related to body image were identified: (1) stigma-related concerns, and (2) narrowed options for self-presentation.

This study revealed that breast cancer survivors with lymphedema may have stigma-related concerns. These concerns can be described in terms of uneasiness in public and avoidance. Some participants felt embarrassed that others noticed their swollen arm, and other participants experienced uneasiness after strangers would make a comment about the appearance of their arm. Participants attempted to change the subject or deflect attention when embarrassed about their arm. Some participants avoided going out in public for important events. They expressed fear about going to job interviews, parties, and other social situations. Thus, they hid from society. These findings are consistent with previous studies that have demonstrated that

lymphedema often has a negative psychosocial impact because it may promote less social contact [32].

Participants mentioned avoidant coping strategies related to dealing emotionally with the changes in their appearance, facing shopping challenges, and avoiding social situations. Avoidant coping strategies involve using mental or behavioral approaches that allow individuals to avoid dealing directly with a stressor, thereby escaping from uncomfortable thoughts and situations [35]. Avoidant behavior results in withdrawal and a narrowing of a person's behavioral repertoire. This withdrawal results in more passive behaviors, rather than active coping behaviors or displays of initiative to tackle difficult problems. Participants reported withdrawing from social situations, which potentially diminishes the important coping resource of social support. Avoidant coping has been associated with less effective immune functioning, depression, less adherence to prescribed regimens, disease progression, and poor adjustment [36-39].

This study also revealed that breast cancer survivors with lymphedema have difficulty finding apparel. This led to narrowed options for self-presentation and created barriers to adapting to body image changes. The inability to wear certain types of clothing they had worn in the past was a profound loss for many participants. The time spent seeking workable clothing options was frustrating and, at times, futile. Participants expressed frustration at limited clothing options for purchase due to the asymmetry of their limbs. Some participants were no longer able to receive clothing from friends and family for holiday and birthday presents because of the difficulty in finding items that fit properly. Participants were also frustrated that their clothing selection was not based on their style or preference, but rather dictated by the size of their swollen arm.

This asymmetry in their arms often resulted in having to buy a larger size than the rest of their body needed. Participants also expressed exasperation at their changing arm volume interfering with the fit of clothes they already owned. Additionally, some participants wished that they could wear jewelry, such as rings, on their affected arm. These findings are supported by previous qualitative interviews in which participants also mentioned difficulties with clothing [30,32]. These frustrations and unwelcome alterations in body image add to a list of substantial losses associated with lymphedema and serve as a constant reminder that although they survived cancer, they are now different. They are held down by these changes.

A key strength of this study is the use of investigator triangulation, peer debriefing, checking of verbatim transcriptions, and use of a decision trail. However, findings from this study should be considered in light of its limitations. First, given the sample composition, the results of this study might best apply to middle-aged breast cancer survivors with lymphedema. Second, that focus group questions were not specifically directed to solicit body image-related issues. Questions that target this area could elicit more robust findings. Given the unprompted vocalization of body image concerns by the participants, body image would appear to be an important issue to address in this population. Third, individual interviews were not undertaken, which may have impacted disclosure content.

Despite these limitations, the patterns of hide and seek as strategies to deal with body image issues have been identified as problematic, stressful concerns for this subgroup of breast cancer survivors with lymphedema.

There are several important implications for health care practice that can be gained from this study, as this pattern of hiding from

others and continually seeking options for self-presentation creates emotional distress. First, health care providers should assess breast cancer survivors with lymphedema for these body image-related difficulties and behavior patterns. Many patients may not mention these issues if not asked. Additionally, healthcare providers and researchers should take the lead in developing practical, supportive interventions to improve the body image of breast cancer survivors with lymphedema. In particular, interventions that promote approach coping rather than avoidant coping could help patients manage their body image frustrations more effectively. Patients should be informed about the risks of pursuing avoidant coping patterns with respect to social support, depression, and physical well-being. Instead of relying on denial, repression, and withdrawal, patients could be encouraged to manage others' reactions effectively and reframe their basis of self-worth. Accepting limitations that cannot be changed, while aggressively trying to change aspects of life that are malleable, also promote better mental health. Lymphedema is a challenging condition on many levels, but patients can experience better quality of life if they can learn more effective coping skills to deal with the emotional and physical frustrations associated with unwelcome alterations in body image.

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