



Published in final edited form as:

Cancer Nurs. 2012 January ; 35(1): E18–E26. doi:10.1097/NCC.0b013e31821404c0.

Voices from the Shadows: Living with Lymphedema

Sheila H. Ridner, PhD, RN, FAAN, Candace M. Bonner, BA, RN, Jie Deng, PhD, RN, and Vaughn G. Sinclair, PhD, RN

Vanderbilt University School of Nursing, Nashville, TN.

Abstract

Background—Breast cancer survivors with lymphedema face a lifetime of stressful physical and emotional symptoms and challenging self-care demands. An in-depth understanding of the perceptions and feelings surrounding life with lymphedema is critical to developing effective supportive care approaches.

Objective—To explore perceptions and feelings related to lymphedema in breast cancer survivors.

Method—The expressive writings of 39 individuals were evaluated for this descriptive qualitative study. Data were analyzed using conventional content analysis.

Results—Qualitative analyses produced four major themes: (1) marginalization and minimization; (2) multiplying losses; (3) yearning to return to normal; (4) uplifting resources. Sub-themes for each major theme were also identified.

Conclusion—The lymphedema experiences of breast cancer survivors reveal perceptions of marginalization from healthcare providers who are not well informed about lymphedema management and minimize its impact. Multiple distressing losses confront these patients on a daily basis, including body image disturbances, loss of functionality and control over time, permanent uncertainty, and adverse effects on relationships. The daily challenges of lymphedema often result in cumulative frustration and resentment that contribute to failure to perform self-care. Normalcy has been lost, never to return. These women find solace, encouragement and hope to meet the challenges of lymphedema through support from others and their spiritual beliefs.

Implication for Practice—Healthcare providers need greater awareness of the physical and psychosocial effects of lymphedema in breast cancer survivors. Nurses have unique opportunities to serve as advocates for reducing perceived marginalization and promoting effective self-care and other activities that promote psychological well-being and reduce physical deterioration.

Keywords

Lymphedema; Breast Cancer; Marginalization; Psychosocial Stress; Cancer Treatment Late-effects; Qualitative Research; Women's Health

Breast cancer treatment is the leading cause of secondary lymphedema in developed countries.¹ Breast cancer survivors with lymphedema often describe having lymphedema as being worse than having had breast cancer.²⁻⁴ Lymphedema casts a long shadow. It serves

Correspondence: Sheila H. Ridner, PhD, RN, FAAN, Vanderbilt University School of Nursing, 525 Godchaux Hall, 461 21st Avenue South, Nashville, TN, 37240 (sheila.ridner@vanderbilt.edu).

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

as an unpleasant daily reminder of the breast cancer experience. It has lifelong physical, psychological, and social consequences. For instance, physical symptoms may include progressive swelling, pain, fatigue, and impaired limb mobility;^{3, 5} psychological symptoms involve anger, fear, and loss of confidence in their bodies.^{6, 7} The symptoms associated with lymphedema may partially explain why breast cancer survivors with lymphedema have a poorer quality of life than breast cancer survivors without lymphedema.^{6, 8}

Current treatment of lymphedema focuses primarily on reducing the size of the affected arm. Unfortunately, even after successful treatment to reduce arm size, individuals with lymphedema not only face a lifetime of stressful, at-home self-care, such as wearing compression sleeves and avoiding activities that may increase the risk of developing swelling and infection in the arm, but continue to have physical and emotional symptoms related to the chronic nature of lymphedema. Therefore, in addition to therapy to reduce arm size, supportive care interventions are needed to improve health outcomes and improve the quality of life in breast cancer survivors with lymphedema. An understanding of the emotions and feelings surrounding the lives of breast cancer survivors with lymphedema is critical to developing effective supportive care approaches.

Participants in this study comprised the experimental group of a larger, two group, parent randomized clinical trial (RCT) in breast cancer survivors with chronic Stage II lymphedema (analysis in progress). The primary objective of the parent RCT was to compare the effectiveness of structured expressive/emotion based writing to fact-only writing on physical and psychological symptoms and quality of life in this patient population.⁹⁻¹² The objective of the study reported in this manuscript was to examine the deepest thoughts and feelings expressed by breast cancer survivors about how breast cancer treatment-related lymphedema impacted their lives.

Methods

Instructions for the qualitative writings from which these data are gleaned were based upon Pennebaker's Expressive Writing Paradigm.⁹⁻¹² Participants in the parent study were recruited by contacting individuals in an existing breast cancer database who had previously given permission to be contacted for future studies, through an advertisement posted on-line through the hospital communications department, via the National Lymphedema Network website, and from brochures distributed to lymphedema therapists, oncologists, cancer centers, breast surgeons, YMCA's, and other breast cancer support groups. Snowball sampling also took place as many participants contacted fellow breast cancer survivors with lymphedema and told them about the study. All participants were between 21 years and 80 years old, could read, write, and speak English, and had no evidence of metastatic disease. Individuals were not eligible for the parent study if they were undergoing intravenous chemotherapy or radiation therapy, had medical conditions that could cause edema, could not stand upright for measurement of height and weight, or had a history of suicide attempts, recent suicidal ideation, or were taking antipsychotic medication. Institutional Review Board approval was granted and written informed consent was obtained from all participants.

Writings from the 52 experimental participants in the parent study were placed in a random order and analyzed until thematic saturation was achieved. Saturation was achieved at the 39th participant. Therefore this study consists of data from a total of 39 women with breast cancer treatment-related lymphedema.

Data Collection Procedures

The following instruments were used for data collection:

Demographic Questionnaire—Data included date of birth (used for calculating age at diagnosis and enrollment), years of education completed, race, marital status, income, employment status, the presence of any concurrent medical conditions, current medication use, height, weight, area of residence, and insurance.

Breast Cancer and Lymphedema History/Treatment forms—Data included date of diagnosis of breast cancer/lymphedema, location, stage of disease, and type and dates of treatment.

Writings—Participants were asked to write their deepest thoughts and feelings about their lymphedema and its treatment. Precise writing instructions are included in Table 1. These writing sessions were spaced over two weeks and each week's writings were spaced 48 hours apart to allow time for rumination. The writings took place in the privacy of the participants' homes. They could write either with pen and paper, or on-line at a confidential study website. Participants were called by the study staff prior to their chosen assigned time to start the writing. After each twenty minute writing, the study staff called the participants to direct them to stop writing. Because participants were instructed to write about their deepest thoughts and feelings, during the stop call, as a safety measure, they were asked "Did you experience any problems while writing?" If yes, and if the person was distressed, they were asked after talking to the study staff, if they would like our study psychologist to contact them. No one requested this contact. In order to evaluate trustworthiness of the data, in real-time, at the conclusion of each session participants completed a member checking questionnaire. Using a seven point rating scale with anchors of 1=not at all and 7=a great deal, they answered: How personal did you consider your essay to be? To what degree did you reveal emotions in your essay? To what degree have you previously held back telling others about the subject you covered in your essay?

Data Analysis

SPSS Version 17.0 was used for analysis of quantitative data. Descriptive statistics were used to describe the sample, including demographic data, breast cancer disease and treatment data, and lymphedema disease and treatment data. Responses to the three-item member checking questions were also analyzed using descriptive statistics.

Data were analysed by using conventional content analysis.¹³ Handwritten narratives were transcribed verbatim. Online narratives did not require transcription. Each writer was assigned a number that did not reflect the study identification number so the coders were blinded and each writing session was assigned a number (e.g., 615.2 indicates writer 615's second writing session). Coders included the primary author, one master's prepared registered nurse, a bachelor's prepared social worker who was also a registered nurse, and a bachelor's prepared research assistant. Coders began by initially reading the narratives from beginning to end to form a general impression of the writings.¹³⁻¹⁵ They then read line-by-line, highlighting key text, and noted in the margins keywords or phrases that portrayed a thought or feeling using the participants own words. Coders placed developing codes in table containing over 400 items and met multiple times to examine the codes and reach consensus. Fifteen broad codes were identified.^{14, 15} The primary author then completed a set of electronic notes to clarify thoughts about the codes and to determine connections between them. Some codes were combined and remaining codes were then sorted into categories for thematic interpretation.

DEMOGRAPHIC RESULTS

Demographic data of the study participants are summarized in Table 2. The average age was 55.62 years ($SD=10.03$). Disease and treatment data are presented in Table 3. Time since breast cancer diagnosis was 8.49 years ($SD=6.77$). The lymphedema duration was 5.64 years ($SD=4.10$).

QUALITATIVE RESULTS

The themes addressed the intertwining areas of physical, psychological, and social areas of concerns of breast cancer survivors with treatment-related Stage II lymphedema. Four major themes were identified: marginalization and minimization; multiplying losses; yearning to return to normalcy; and uplifting resources. Themes are presented below, with specific participant (615) and writing session (.1) numbers listed before their commentary. In an attempt to assess the participants' perception of the writing experience and the credibility of the data from an emotional perspective, the post-writing questionnaires completed by all participants were assessed. The questionnaire data revealed that participants consistently reported that their writings were personal and emotional (refer to Table 4).

Theme 1: Marginalization and Minimization

Marginalization is defined as, "to relegate to an unimportant or powerless position within a society or group".¹⁶ This theme was present in writings of 35 of the 39 (90%) participants. They conveyed their disappointment in others who failed to understand the complexity and impact of their lymphedema-related problems. These women discussed lack of support from healthcare providers, which contributed to disease management failure, along with lack of funding from the healthcare system and lack of sensitivity from friends and family.

Subtheme: Lack of support from healthcare providers—Many women ($n=29$, 74%) clearly felt that healthcare providers who had the power to help them minimized the importance of lymphedema and its associated problems. One participant, (615.2), explained, "Lymphedema is like a chain around my neck. I don't understand why science and research cannot find ways to treat it more effectively. I get peeved when I think that someone just doesn't think it is as important as other illnesses."

Some women attempted to explain why the marginalization occurred and directly attributed their marginalization to gender bias: (620.2) "If more men got lymphedema than women, more research would be done and doctors would take it more seriously." Regardless of the cause, such marginalization leads to feelings of overt bitterness towards the healthcare professionals, (620.3) "I wish that doctors would be more sensitive toward the matter (lymphedema) and act like they care instead of acting like women should just be glad to be alive."

Marginalization was also reflected by comments concerning gratitude for the simple opportunity to participate in lymphedema research, (601.4) "It is very encouraging that someone cares enough to even do a study about this condition and the effect that it has on our lives."

Subtheme: Disease management failure—Some ($n=23$, 59%) felt marginalized by the medical community due to healthcare providers' lack of knowledge about lymphedema and inconsistent approaches to lymphedema management. They reported that uninformed and inconsistent treatment by healthcare providers often contributed to disease management failure and worsening lymphedema, (624.2) "Whenever I reminded people of no needles, no

BP cuff, I felt that I was complaining and whining. This made me feel resentful that the very people I was relying on were not well informed.”

Mixed messages and general lack of knowledge across healthcare providers about effective lymphedema management could contribute to disease management failure, (648.2) “I have gotten different answers from different people regarding activity with the affected arm. My general surgeon says to treat it completely normal, lift whatever I want, do whatever I want, etc. The lymphedema therapist of course says otherwise.”

Participants also expressed concerns about the quality of care received from individuals who provide manual therapy, (620.4) “Speaking of physical therapists - I have had some experiences with some who were not very good and knew just enough to say they were qualified to treat lymphedema.”

Subtheme: Lack of financial support from the healthcare system—Healthcare systems issues also reinforced the marginalization experienced by some these women (n=13, 33%). For example, failure of third party payers to fund or only partially fund expenses for physical therapy and self-care items such as compression garments were commonly noted, (624.2) “Whenever I had to have a sleeve and a custom made glove my insurance wouldn’t pay. [...] I had a feeling of being abandoned and shoved aside.” One participant stated, (605.1) “I can buy a new boob once a year but I cannot buy the newest machine that has shown improvement in my back swelling.”

Many perceive they are treated more poorly than others with different chronic medical problems or even those with cosmetic concerns. (601.3) “Do you think patients with heart disease, high blood pressure or diabetes are told to go home and try things until they figure out what works? I won’t even get started on the compression sleeves that I buy two at a time twice a year. Insurance doesn’t touch that but I did notice with my new dental policy they will pay 80% of teeth bleaching. Seriously now, does anyone else see that this doesn’t make sense? Teeth bleaching, really?”

Subtheme: Lack of sensitivity from friends and family—A lack of understanding about lymphedema from family, friends and community creates a greater sense of marginalization and isolation and 21 (54%) wrote about this, (611.2) “My son and parents don’t see the big deal and think I’m being weird for letting this bother me. [...] They all say, ‘Well, at least the cancer isn’t back.’ ”

Theme 2: Multiplying Losses

The condition of lymphedema presented almost all of these women, 36 out of 39, (92%) with a cascading series of negative events, affecting body image, functionality, and control of time due to the demands of disease maintenance. Looming uncertainty became a part of their lives. Lymphedema also adversely impacted several aspects of social support.

The complex and intertwined losses attributed to lymphedema presented challenges that affected almost every aspect of their lives. Comments related to body image disturbance were noteworthy,^{2, 3, 17} as were remarks about the enormous daily investment of time and energy required to keep lymphedema from progressing.

Subtheme: Body image disturbance—Two-thirds, (n=26), of the women expressed persistent concerns with the appearance of arms, hands and trunk swelling. Internal perception and external commentaries contributed to a negative body image.

Negative terminology, coupled with anguish, was frequently used to describe their limbs, (629.3) “My arm is fat. I think it is ugly. I have to be careful. To me it looks like someone else’s arm, like a big lobster claw attached to my shoulder.” (638.4) “I call my arm my Popeye arm. See what happens when you eat your spinach? I wish it were as strong as it looks. It’s heavy and hurts.”

Many felt damaged, (602.4) “I don’t feel ugly, just not beautiful. I feel scarred, lopsided, and swollen. I don’t like to use the word damaged but that’s what comes to mind.”

In addition to their own perceptions, body image disturbance can be affected by remarks from others, as illustrated in this remark, (638.1) “I just don’t like the staring and the questions. It’s like I should wear a sandwich board saying what it is with a big explanation.” For many, warmer months are more difficult to tolerate as camouflaging, long-sleeve clothing is impossible to wear and heat increases swelling making the compression garments uncomfortable. For some, the winter months grant a slight reprieve from some outside scrutiny, as they disguise the arm with clothing. (638.2) “I like the cold weather. This time of year I can cover up my arm better. I still can’t get on a winter coat but at least I can wear a huge sweatshirt with a vest. When I have to go someplace that I can’t wear a sweatshirt, I get depressed and very angry and I usually end up not going.” Clearly, body image disturbance may result in self-imposed social isolation for some.

Subtheme: Loss of control over time—The demands of caring for this condition captivate and consume precious time on a daily basis for some of the participants (n=17, 44%). As one woman stated, (604.1) “I truly resent the time that I have had to spend trying to take care of this arm and feel it will never go down.” Another woman remarked, (602.4) “So much of my time and my husband’s is now taken up by appointments, exercise, bandaging, and washing bandages. It’s time I can’t get back and time is so very precious once you’ve been through cancer.”

Subtheme: Loss of function—Perceived loss of function and independence was noted in both work and home environments in over half of the women (n=24). At work, (603.2) “I have to ask for help at work when lifting heavy things and I feel like people just think I am a wimp or something.” This remark suggests that lymphedema may impact vocational pursuits. Basic activities of daily living such as shopping and housekeeping are also impacted. In the home environment, women had to limit their activities, (648.2) “He (doctor) says not to lift over 5 lbs., no vacuuming, no repetitive motions, otherwise baby it. I do not like the idea of having to always be aware of what I might be doing to my arm. I want to do things normally.” These restrictions were repetitive sources of frustration.

Subtheme: Permanent uncertainty—As a progressive condition, lymphedema carries with it the uncertainty of greater debility if the condition worsens over time. Many of the participants, 51%, (n=20), lived in fear that their fragile condition would deteriorate dramatically.

Fear of infection, prompting modification in normal activities to reduce infection risk, was common, (650.2) “I have had my share of cellulitis infections. [Sic]... no longer get to enjoy several outside activities due to fear of mosquito bites, brush scrapes, etc.”

Fear of worsening lymphedema was also present, (602.3) “I wish I could go to bed at night and wake up without a scar, or a dent in my breast, and swelling in my arm and hand. Most of all ... no worry about will it come back? What if I get a really bad infection? What if my lymphedema gets worse?”

Fear about declining functional abilities and increased healthcare needs as they age exist as well, (601.4) “It seems to be a very scary future. To think that I could live another 30-40 years with the size of what my arm/hand could become is very scary and depressing.” (602.4) “Will I be able to do the things I’ve always done?”

Reminders of cancer and thoughts of death were also present, (605.1) “Having cancer is not as bad as having lymphedema. The breast is gone, the treatments are over and it is in the past. Lymphedema on the other hand is constant.” (629.1) “I now had a physical reminder of my journey through hell. My constant companion, an enlarged arm, was a continuous reminder.” Their future remains uncertain, as this progressive condition can powerfully affect their functionality, emotional challenges, and longevity.

Subtheme: Adverse effects on relationships—Some women, (n=16, 41%) expressed guilt about being a burden to their loved ones, (602.2) “I feel guilty about being the one who causes all of the worry, extra work, exhaustion, and boredom.” For others, lymphedema created an invisible barrier between them and their loved ones, (666.3) “I cannot lift my nieces and nephews or tote them around like I used to. I can’t hold them in my arms and it makes me feel as though I can’t be close to them.” As noted in comments about disturbed body image, some women isolated rather than attend social events when they could not adequately conceal their damaged extremity. Frequent social embarrassment and selection of isolation reflects another loss attributable to lymphedema.

Subtheme: Impact on psychological well-being—The majority of women (n=25, 64%), face multiple losses that intertwine and affect every aspect of their lives. Frustration and anger over marginalized, inadequate healthcare treatment can surface with every encounter with the healthcare system. In addition, these women face repeated disappointment over the minimization of their condition by others who do not understand the enormous daily challenges of living with lymphedema. The sadness and anger associated with grieving losses were frequently expressed, (615.1) “I really do believe the quality of my life has changed and much of it cannot be returned. It makes me very sad. I was really angry about it at first, now I am just sad.” (618.2) “How have I felt about the lymphedema diagnosis? Frustrated, angry, sad, and perplexed.”

Theme 3: Yearning to Return to Normal

Seventy-seven percent, (n=30), of the participants in this study expressed strong desires to return to their “pre-lymphedema” self. Lymphedema, not breast cancer itself, had changed their core self-identify. Cancer could be cured, breasts altered by surgery could be hidden underneath clothes, and activities of life could be resumed after successful cancer treatment. Lymphedema could not be cured or easily hidden, and it brought with it many changes in activities and hobbies. They reluctantly became someone with a chronic disease, similar to a diabetic, facing a lifetime of self-care and constant monitoring of “the arm”.

Subtheme: Frustrated aspirations for normalcy—A predominant theme in the writings of 28 (72%), of the women was a loss of their normal self after lymphedema development. This loss was found in many aspects of their lives. In general, (696.1) “I don’t want to be easily identified as being sick. I am not sick! I am a survivor, I can make a full recovery. I don’t want people to look at me funny, I don’t want people to pity me. I just want to look and feel normal again.” (638.1) “Finding clothes that fit my arm is getting harder and harder, that’s depressing. All I ever wear is tee shirts and stretchy things.”

The desire to return to normal was profound, (602.2) “I want to do everything I was able to do before and the hell with the swelling. The last thing I want is to feel like an invalid or

someone who uses it (lymphedema) as an excuse not to do anything.” (615.2) “The fact that I now have to live with so many restrictions on how I do my daily routine is something I have not come to terms with.” Unfortunately, for these women normalcy was lost, never to be rediscovered. (628.1) “Cancer changed me for a short time. Lymphedema changed me for the rest of my life.”

Subtheme: Damaging attempts to regain a sense of normalcy—Some (n=14, 36%) of these women become defiant about their debilitating condition and the self-care demands. They become non-compliant with their care, perhaps in a futile attempt to regain their former “normal” lifestyle and recapture time involved in lymphedema care. Despite the consequences, in frustration and defiance of the demands of caring for a condition that would not improve, women choose to quit battling this inexorable condition. As one woman remarked, (624.1) “My arm was massaged and wrapped several times a week. The swelling didn’t go down. I was prescribed a glove and sleeve which I wore religiously for quite a long time. But the appearance of my hand and constant comments about my sleeve became embarrassing to me. I quit wearing my sleeve.” (620.1) “I don’t like having lymphedema but I don’t take care of myself like I should. I don’t wear my glove and sleeve daily. I don’t wrap like I should and I don’t sleep in my Jovi.” (638.1) “I use a compression machine twice a day for an hour. [...] Some days I just skip it and know I’m only hurting my arm.” These women long to return to “life before lymphedema,” and they have chosen to act as though they do not have the condition, despite the consequences.

Theme 4: Uplifting Resources

During the third and fourth writings, participants (n=30, 77%), began to express some feelings that indicated that in the midst of all the negative, emotional draining feelings associated with their lymphedema, some positive feelings were also present. These positive feelings centered around perceived support from other people and strength gained from belief a higher power assisted them in coping with this chronic disease. Other people and God appear to have a positive, fortifying, effect on breast cancer survivors with lymphedema and partially fill the void they experience from societal marginalization. The women in this study offered moving stories of the encouragement of friends and family members, coupled with their acceptance and willingness to help in any way.

Subtheme: Psychosocial support—Spouses, family members, friends, and coworkers provide are the most common sources of direct care, comfort, and encouragement, as 24 (62%) cited these supports. (631.4) “My husband wraps my arm and hand most every night.” In addition to providing emotional and instrumental support, family and friends often offer acceptance, which may prompt those with lymphedema to accept themselves. One woman stated, (640.4) “I have wonderful friends and family. They take me as I am and are very concerned about what I call my leftovers from cancer. I don’t think I could ask for better people in my life.”

Because lymphedema is a chronic lifelong condition, it is important to have a positive social support system, (626.4) “My husband has been very supportive with this. He wants to know about it as well, and so do my friends and family. I share with others about lymphedema who are going through Breast Cancer, and I hope that I will help others.” Knowing that others will provide instrumental support may give these women hope that they can manage whatever comes in their uncertain future.

Subtheme: Spiritual resources—Religious beliefs served as vehicles of acceptance for the tough, unchangeable realities of their lives for 16 (41%) of participants. These beliefs and faith in God provided psychological comfort and many participants had reframed their

lymphedema experience into one of personal triumph, (640.4) “I am truly blessed to be able to somewhat go on with my life and my family dealing with what God has dealt me. He doesn’t waste your pain. There is life after cancer with lymphedema”.

Many women shared the following sentiment, (666.4) “I am living with this condition everyday but not as an invalid but as a survivor. God spared my life and lymphedema was part of the package. That’s OK when you consider the alternative.” Religious beliefs also served as vehicles of hope, (633.4) “There is the ultimate hope beyond this world where there won’t be illness or side effects. I am grateful for that hope.”

DISCUSSION

Themes discussed in this article portray lymphedema as a severe, unaddressed, issue influencing all facets of the participant’s lives. They indicate that women with Stage II secondary lymphedema suffer considerable physical, psychological, and social disturbances. The study revealed that a common, critical issue was marginalization, a theme that had not been discussed in depth in previous studies. In two prior qualitative studies,^{3, 17} women who experienced lymphedema after breast cancer treatment expressed abandonment by the medical community as a predominant concern, a concept similar to marginalization. However, marginalization in the context of uninformed care and minimization of lymphedema has not been discussed. Analysis of the writings in this study revealed several aspects of perceived marginalization for these women. First, many of the women in the study felt marginalized by the medical community due to a lack of information and inconsistency of protocols for their lymphedema treatment. These women had not been formally abandoned by the healthcare community, but they did not understand why lymphedema seemed minimized and deemed less important than other medical conditions. Second, this realization was compounded by the perceived apathy and neglect from third party payers. Finally, some of women also felt marginalized by their family, friends, and others based on perceived insensitivity to their challenges of living with lymphedema.

Disease management failure has not been reported in previous related qualitative studies. In this study, several participants relayed a failure to manage their lymphedema, and almost all participants remarked that healthcare providers could not manage lymphedema appropriately.

Participants noted many losses and limitations in their activities at home and work that frustrated them, and they felt guilty about being a burden to others because of the effects of lymphedema. In many ways, lymphedema altered relational patterns, whether by preventing activities such as holding children or prompting self-isolation due to concerns about appearance. In the backdrop, uncertainty about the potential of worsening lymphedema with its associated effects on appearance, function, time demands and relationships colored their perceptions of the future. As these women faced losses on a daily basis, the psychological challenges were profound, and they provided heart-rending accounts of dealing with frustration, sadness, and anger about their compounding losses.

Loss of normalcy, as a theme, has been reported in the literature in this population.^{3, 18} The participants in this study had lost control of their bodies, their self-image, their ability to function in various roles, and their independence. They yearned to return to “normal” – the state and condition of their lives before lymphedema drastically altered their existence. Noncompliance with treatment was a pattern in this data. This behavior may be attributed to damaging attempts to regain a sense of normalcy born out of great frustration and exhaustion with the demands and challenges of lymphedema.

Uplifting resources were also identified by the women. Similar to previous study findings,^{2, 18} many breast cancer survivors with secondary lymphedema obtained important psychological support from their family members, friends, and coworkers. This emotional and instrumental support was highly valued and provided the women with a vehicle for acceptance and hope that they could meet the challenges of living with lymphedema. Spiritual beliefs also offered a resource for acceptance and hope.¹⁸⁻²⁰

Strengths and Limitations

This study has several strengths. It is the only known study that gives voice to these marginalized individuals by providing rich descriptions of the intense and poignant beliefs and feelings of breast cancer survivors with lymphedema. It is, with 39 participants, the largest qualitative study to date in this population. Another strength was that the study participants were recruited from seven different states which included southeast, mid-west, northeast, and western areas of the United States. Because of this geographic diversity, the study outcomes may be transferable to similar patients in other areas of the United States. Despite these strengths, there are some limitations. Approximately eighty percent of the participants were Caucasian women, so the findings of this study may not represent breast cancer survivors with secondary lymphedema from different ethnic backgrounds. Moreover, the study only recruited breast cancer survivors with Stage II lymphedema. Therefore, the outcomes of this study may not represent breast cancer survivors with other stages of lymphedema. Another limitation is that these women volunteered to participate in this study, so the findings may be different for patients who would be unwilling or disinterested in an expressive writing study.

CONCLUSIONS

The experiences of the breast cancer survivors with lymphedema in this study have provided a portrayal of their poorly understood, shadowed lives. The psychological distress, body image disturbances, perceptions of loss, and frustration with healthcare providers contribute to a sense of marginalization. The emotional and physical exhaustion of meeting the daily challenges of lymphedema often result in frustration, defiance, and resentment. The data underscores that these women find solace and encouragement to meet their challenges through support from others and spiritual beliefs, but find little support from their healthcare providers. Both patient-centered and healthcare systems interventions are needed to address the multiple issues identified in this study.

Implications for Nursing Practice

Marginalization is an overwhelming problem for breast cancer survivors with lymphedema. Nurses are well positioned to assume an active role in educating fellow nurses, other healthcare professionals, third party payers, patients, family members and the general public about the physical and psychosocial effects of lymphedema in breast cancer survivors. To accomplish that goal, however, these findings suggest that nurses themselves need to become better educated about the etiology of the disease and be trained in skills to identify physical (e.g., swelling, odd sensations in the arm) and psychosocial (e.g., psychological distress, body image disturbance) sequelae of the condition. Academic institutions can play a critical role in addressing the needs of this population through inclusion of lymphedema-related content in their training curriculums and work with professional organizations to develop continuing education programs to address these deficits. Development of multi-disciplinary educational offerings would be beneficial since participants in this study identified deficits in care across multiple healthcare professions.

Nurses have the unique opportunity to interact with breast cancer survivors and instruct them on the importance of lymphedema self-care, as well as when to seek professional treatment. In addition to emphasizing avoidance behaviors for lymphedema, nurses could promote social activities and physical exercises that serve the goal of returning the patient to more normal function. Development of multi-disciplinary protocols/guidelines for routine lymphedema assessment, education, management, and supportive care is also indicated to address marginalization and disease management issues. These protocols should underscore the importance of identifying psychological barriers to continued self-care and offer intervention strategies that promote psychological well-being and persistent adaptive coping in this population.

Implications for Research

If patient care is to improve, further research is clearly needed to determine effective teaching strategies for healthcare professionals regarding the etiology of lymphedema, lymphedema assessment skills, and patient management. Additional research is needed to develop lymphedema assessment standards. Longitudinal studies examining patients' psychological status and long-term coping patterns could help identify predictors of noncompliance. Intervention studies could be developed to explore effective strategies for managing the physical and psychosocial impact of lymphedema.

Acknowledgments

Funded by a grant from the American Cancer Society

References

1. Rockson SG. Lymphedema. *American Journal of Medicine*. 2001; 110(4):288–295. [PubMed: 11239847]
2. Armer J, Heckathorn P. Post-breast cancer lymphedema in aging women: Self-management and implications for nursing. *Journal of Gerontological Nursing*. 2005; 31(5):29–39. [PubMed: 15916201]
3. Greenslade M, House C. Living with lymphedema: A qualitative study of women's perspectives on prevention and management following breast cancer-related treatment. *Canadian Oncology Nursing Journal*. 2006; 16(3):165. [PubMed: 17523577]
4. Shih Y-CT, Xu Y, Cormier JN, et al. Incidence, treatment costs, and complications of lymphedema after breast cancer among women of working age: A 2-year follow-up study. *Journal of Clinical Oncology*. 2009; 27(12):2007–2014. [PubMed: 19289624]
5. Armer JM, Radina ME, Porock D, Culbertson SD. Predicting breast cancer-related lymphedema using self-reported symptoms. *Nursing Research*. 2003; 52(6):370–379. [PubMed: 14639083]
6. Ridner S. Quality of life and a symptom cluster associated with breast cancer treatment-related lymphedema. *Supportive Care in Cancer*. 2005; 13(11):904–911. [PubMed: 15812652]
7. Sneddon M, Lewis M. Lymphoedema: A female health issue with implications for self care. *British Journal of Nursing*. 2007; 16(2):76–81. [PubMed: 17353815]
8. Heiney S, McWayne J, Cunningham J, et al. Quality of life and lymphedema following breast cancer. *Lymphology*. 2007; 40(4):177–184. [PubMed: 18365532]
9. Pennebaker JW. Theories, therapies, and taxpayers: On the complexities of the expressive writing paradigm. *Clinical Psychology: Science and Practice*. 2004; 11(2):138–142.
10. Pennebaker JW. Putting stress into words: Health, linguistic, and therapeutic implications. *Behaviour Research and Therapy*. 1993; 31(6):539–548. [PubMed: 8347112]
11. Pennebaker JW, Graybeal A. Patterns of natural language use: Disclosure, personality, and social integration. *Current Directions in Psychological Science*. 2001; 10(3):90–93.
12. Pennebaker JW, Seagal JD. Forming a story: The health benefits of narrative. *Journal of Clinical Psychology*. 1999; 55(10):1243–1254. [PubMed: 11045774]

13. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*. 2005; 15(9):1277–1288. [PubMed: 16204405]
14. Creswell, J. *Research design: Qualitative, quantitative, and mixed methods approaches*. SAGE Publications, Inc; 2009.
15. Lewis-Beck, M.; Bryman, A.; Liao, T. *The SAGE encyclopedia of social science research methods*. Sage Publications, Inc; 2004.
16. *Merriam-webster dictionary*. Merriam-Webster, Inc.; Springfield: 2010.
17. Carter B. Women’s experiences of lymphedema. *Oncology Nursing Forum*. 1997; 24(5):875–882. [PubMed: 9201739]
18. Hare M. The lived experience of breast cancer-related lymphoedema. *Nursing Standard*. 2000; 15(7):35–39. [PubMed: 11971437]
19. Williams A, Moffatt C, Franks P. A phenomenological study of the lived experiences of people with lymphoedema. *Int J Palliat Nurs*. 2004; 10(6):279–286. [PubMed: 15284623]
20. Fu MR. Breast cancer survivors’ intentions of managing lymphedema. *Cancer Nursing*. 2005; 28(6):446–457. [PubMed: 16330966]

Table 1**Writing Instructions**

“We would like for you to write about your deepest thoughts and feelings about how lymphedema and its treatment has affected you and your life. Really let go and explore your deepest emotions and thoughts. You might tie your topic to your relationships with others, including parents, lovers, children, friends, or relatives, to your past, your present, or your future, or to who you have been, who you would like to be, or who you are now. You may write about the same general issues or experiences on all the days of writing or on different topics each day. Your writing is completely confidential. Do not worry about spelling, sentence structure, or grammar. The only rule is that, once you begin writing, continue to do so for 20 minutes and then stop. Do not put your name on your writing.”

Table 2

Demographic Data

Characteristic	Number (%) (n=39)
Race	
Caucasian	31 (79.5)
African American	7 (17.9)
Other	1 (2.6)
Marital Status	
Single	12 (30.8)
Married	25 (64.1)
Widowed	2 (5.1)
Household Income (US Dollars)	
≥30,000	5 (12.8)
\$30,001-60,000	9 (23.1)
>\$60,000	20 (51.3)
Do not care to respond	5 (12.8)
Education	
12th grade below	9 (23.1)
Beyond 12th grade	30 (76.9)
Work Status	
Employed	27 (69.2)
Unemployed	12 (30.8)
Insurance	
Private Insurance	24 (61.5)
Medicare with supplement	5 (12.8)
HMO	3 (7.7)
TennCare	2 (5.1)
Other	4 (10.3)
Medicaid	1 (2.6)
Residence Area	
City	27 (69.2)
Country/Other	12 (30.8)
Age	
≥65 years old	33 (84.6)
<65 years old	6 (15.4)
Age, mean ± SD (years)	55.31±10.14

Table 3

Disease and Treatment Data

Characteristic	Number (%) (n=39)
Breast cancer-related data	
Location	
left	23 (59.0)
right	13 (33.3)
bilateral	3 (7.7)
Stage at diagnosis	
I	9 (23.1)
II	21 (53.8)
III	8 (20.5)
IV	1 (2.6)
Surgery type	
Lumpectomy/Segmental	17 (43.6)
Modified radical mastectomy	16 (41.0)
Radical mastectomy	3 (7.7)
Other	3 (7.7)
Chemotherapy type	
Cytosin Adriamycin 5Fu	3 (7.7)
Adriamycin Cytosin	10 (25.6)
Cytosin Methatrexate 5fu	4 (10.3)
Other/Missing/None	22 (56.4)
Radiation	
None	11 (28.2)
Some	28 (71.8)
Complete treatment received	
Surgery alone	2 (5.1)
Surgery and radiation	1 (2.6)
Surgery and chemotherapy	9 (23.1)
Surgery, radiation, and chemotherapy	27 (69.2)
Time since breast cancer diagnosis, Mean \pm SD (years)	8.57 \pm 6.74
Lymphedema Data	
Location	
Left arm	23 (59.0)
Right arm	16 (41.0)
Lymphedema dominant arm	18 (46.2)
BMI Group	
<30	19 (48.7)
\geq 30	20 (51.3)
Lymphedema duration, Mean \pm SD (years)	5.75 \pm 4.06
Lymphedema onset since breast cancer diagnosis, Mean \pm SD (years)	2.74 \pm 5.65

Table 4

Member Checking Questionnaire (n=39)

Question	Writing 1 Mean/Median	Writing 2 Mean/Median	Writing 3 Mean/Median	Writing 4 Mean/Median
How personal did you consider your essay to be?	4.95/5.00	5.32/6.00	5.49/6.00	6.03/6.00
To what degree did you reveal emotions in your essay?	5.59/6.00	5.68/6.00	6.03/6.00	6.32/7.00
To what degree have you previously held back telling others about the subject covered in your essay?	3.82/4.00	4.45/5.00	4.31/5.00	3.87/4.00