Factors Associated With Fear of Lymphedema After Treatment for Breast Cancer

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Purpose/Objectives: To identify demographic and treatment characteristics associated with postoperative fear of lymphedema.

Design: Prospective cohort study.

Setting: Outpatient breast clinic at a comprehensive cancer center in the northeastern United States.

Sample: 324 patients undergoing treatment for unilateral breast cancer.

Methods: Women with breast cancer were prospectively screened for lymphedema (relative volume change of 10% or greater) preoperatively and every three to eight months postoperatively via Perometer arm volume measurements. Fear was simultaneously evaluated via questionnaire. Multivariate linear mixed-effects regression models were used to identify factors associated with mean postoperative fear score and to plot the average fear score over time within axillary surgery type subgroups.

Main Research Variables: Postoperative fear of lymphedema.

Findings: Higher preoperative fear score ($p < 0.0001$), younger age at diagnosis ($p = 0.0038$), and axillary lymph node dissection (ALND) ($p < 0.0001$) were significantly associated with higher mean postoperative fear score. The average fear score changed nonlinearly over time ($p < 0.0001$), decreasing from preoperative to 24 months postoperative and leveling thereafter.

Conclusions: Preoperative fear, younger age at diagnosis, and ALND may contribute to postoperative fear of lymphedema.

Implications for Nursing: Individualized education that begins preoperatively, continues throughout treatment, and is re-emphasized 24 months postoperatively may help minimize fear of lymphedema.

Key Words: lymphedema; breast cancer; fear; Perometer; quality of life

ONF, 41(5), 473–483. doi: 10.1188/14.ONF.473-483

Breast cancer survivors are at a lifelong risk of developing lymphedema, a chronic upper extremity morbidity that can occur secondary to breast cancer treatment. Lymphedema is characterized by the abnormal accumulation of protein-rich fluid in the interstitial spaces of the arm, hand, shoulder, breast, or chest wall, and is often accompanied by symptoms of swelling, heaviness, and discomfort (Armer, Radina, Porock, & Culbertson, 2003; Armer & Stewart, 2010). Survivors with lymphedema are at an increased risk for infection (Shih et al., 2009) and may experience functional impairment (Armer et al., 2003). The psychological distress caused by lymphedema can adversely affect body image, lower self-esteem, and increase anxiety (Chachaj et al., 2010; Ridner, 2005). Together, the physical and psychological detriments of lymphedema have been shown to significantly reduce overall quality of life (QOL) (Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Ridner, 2005).

Because of its difficulty to predict, lack of definitive treatment, and negative impact on QOL, many survivors fear developing lymphedema. Even the possibility of developing lymphedema or worsening existing lymphedema has been shown to cause fear and worry among breast cancer survivors (Collins, Nash, Round, & Newman, 2004; Erickson, Pearson, Ganz, Adams, & Kahn, 2001; McLaughlin et al., 2013). As a result, many women engage in risk-reducing behaviors (McLaughlin et al., 2013). Common risk-reduction practices supported by the National Lymphedema Network ([NLN], 2012) include use of compression garments (particularly for air travel), skin care to avoid trauma or injury that may lead to infection (e.g., avoiding skin punctures such as injections or blood draws, use of sunscreen to protect exposed skin), avoidance of limb constriction (blood pressures, tight clothing), and avoidance of extreme temperatures. However, most of these risk-reduction strategies lack scientific evidence supporting their efficacy. Instead, most are based on expert opinion gathered through decades of clinical experience and understanding of the condition's pathophysiology (Cemal, Pusic, & Mehrara, 2011; McLaughlin, 2012; National Lymphedema Network, 2012).

Fear of lymphedema can also affect decisions about engaging in physical activity and exercise. It has

previously been demonstrated that fear of lymphedema leads to avoidance of strenuous upper-body activities (Lee et al., 2009; Sander, Wilson, Izzo, Mountford, & Hayes, 2012). This avoidance is likely due to lack of awareness among survivors and healthcare professionals about the condition and its risk factors, as well as the lack of evidence regarding appropriate risk-reduction strategies (Bosompra et al., 2002; Greenslade & House, 2006; Kwan et al., 2012; Lee, Mak, Tse, & Chan, 2001; Paskett & Stark, 2000; Radina, Armer, Culbertson, & Dusold, 2004; Tam et al., 2012; Thomas-MacLean, Miedema, & Tatemichi, 2005). A report by Sagen, Karesen, and Risberg (2009) suggested that breast cancer survivors should be encouraged to maintain physical activity in their daily lives without restrictions and without fear of developing lymphedema. Others have shown that gradually progressive upper-body weight lifting decreases risk of lymphedema, increases strength, and may even increase QOL (Ahmed, Thomas, Yee, & Schmitz, 2006; Schmitz et al., 2009). Bicego et al. (2009) have shown that exercise positively influences QOL and may be an effective strategy to improve QOL in women living with breast cancer. In addition, the NLN (2013) advised breast cancer survivors not to avoid strenuous activity and encouraged the practice of resistance exercises or weight lifting.

Women who limit use of their upper extremities from fear of lymphedema may not only compromise their QOL, but also expose themselves to the potential consequences of inactivity. These include prolonged arm weakness, functional compromise, and weight gain (Cheema, Gaul, Lane, & Fiatarone Singh, 2008). Fear of lymphedema may also compromise a woman's ability to perform activities of daily living if regular use of the upper extremities is avoided.

Identification of factors that contribute to fear of lymphedema could aid in optimal education about the condition, and potentially increase QOL for patients with breast cancer. The purpose of this study was to identify specific demographic and treatment factors associated with postoperative fear of developing or worsening existing lymphedema.

Methods

Design and Setting

Since 2009 and with institutional review board approval from Dana-Farber/Harvard Cancer Center and Partners HealthCare, women undergoing treatment for newly diagnosed breast cancer at the authors' institution were enrolled in a prospective lymphedema screening trial. This trial is ongoing and serves to identify women with lymphedema who can be enrolled in a phase III intervention trial designed to generate level 1 evidence regarding the efficacy of various treatment strategies including exercise, use of compression garments, and night bandaging (ClinicalTrials.gov identifier: NCT00959985). Each screening assessment includes two components: (a) bilateral Perometer arm volume measurements performed by one of two clinical research coordinators and (b) completion of the Lymphedema Evaluation Following Treatment for Breast Cancer (LEFT-BC) questionnaire, which addresses symptoms, arm function, fear-avoidance behaviors, and QOL. These screening assessments occur preoperatively and every three to eight months after surgery.

The LEFT-BC is a compilation of four previously validated questionnaires, each of which has been validated individually in the respective publications: the Lymphedema Breast Cancer Questionnaire (LBCQ), which assesses symptoms (Armer et al., 2003); the Disability of the Arm Hand and Shoulder (DASH), which evaluates function (Beaton et al., 2001); the Survey of Arm Care Following Breast Cancer, which addresses fear-avoidance behavior (Lee, Kilbreath, Sullivan, Refshauge, & Beith, 2007); and the Functional Assessment of Cancer Therapy for Breast Cancer (FACT-B), which assesses QOL (Coster, Poole, & Fallowfield, 2001). The LEFT-BC was formatted to apply to women with and without lymphedema to investigate the relationship between the quantitative measure of arm volume change, as measured by the Perometer and symptoms, function, fear, and QOL as they relate to lymphedema. Ultimately, the authors sought to compare and contrast these measures between women who do and do not develop lymphedema.

The data for this report were collected from 2009–2012. Participants were women who were already enrolled in the previously described lymphedema screening trial. Responses to the fear-avoidance section (six statements) of the LEFT-BC were evaluated to assess the fears and perceptions of lymphedema. When possible, patients were asked to complete the LEFT-BC prior to revealing results of the Perometer measurements. However, instances occurred in which patients were unable to complete the questionnaire before needing to leave the facility; therefore, these patients were provided with a paper questionnaire to fill out and return within two to three weeks. However, this accounts for a minority of questionnaires included in the current analysis.

Participants

All women included in this analysis provided their written informed consent prior to their inclusion in the study. All participants were enrolled preoperatively. As part of the enrollment phase, one of two trained clinical research coordinators verbally educated each woman about lymphedema and its known risk factors. The verbal educational content was standardized. A lymphedema fact sheet was provided to those women who requested more details, which gave additional information

about risk-reduction practices and treatment. This fact sheet was compiled by a credentialed lymphedema physical therapist; a team of medical, surgical, and radiation oncologists; and oncology nurse practitioners. In addition, the LEFT-BC provided participants an explanation of lymphedema, describing the condition as a "swelling of the arm, hand, shoulder, or upper body on the side where your cancer was treated."

Demographic and treatment data were collected via medical record review. Of note, women in this study were seen and treated by one of four experienced breast surgeons. Those who underwent bilateral breast surgery and those with metastatic disease were excluded from the analysis.

The authors hypothesized that physical activity level at work influences women's perceptions and fears about lymphedema. Women who are more active at work may be more concerned about developing a lymphedema that may hinder their occupational responsibilities. Alternately, women may be more fearful of worsening an established lymphedema given the physical requirements of their occupation. To evaluate occupation physical activity level, the authors used occupation summary metabolic equivalent (MET) values (Tudor-Locke, Ainsworth, Washington, & Troiano, 2011). Tudor-Locke et al. (2011) assigned single and specific summary MET values to each of the 22 occupation group titles from the 2002 census occupational classification system. These values range from 1.5–4.29 for occupation groups titled "Legal" and "Construction and Extraction," respectively.

Lymphedema

No standardized method currently exists for measuring lymphedema; however, many instruments are available, and the frequency of measurement varies. Available measurement methods include the following: circumferential tape measurement, water displacement, bioimpedance spectroscopy (BIS), and perometry. Although circumferential tape measurement is convenient and cost effective, its accuracy may be compromised because of inconsistent techniques of the examiners (Deltombe et al., 2007). Water displacement is a reliable method, but it is often messy and time-consuming (Fu, Ridner, & Armer, 2009; Ridner, Montgomery, Hepworth, Stewart, & Armer, 2007; Smoot, Wong, & Dodd, 2011; Tewari, Gill, Bochner, & Kollias, 2008). BIS is a reliable and sensitive method that assesses interstitial fluid differences between arms (Ridner, Dietrich, Deng, Bonner, & Kidd, 2009; Smoot et al., 2011; Ward et al., 2011). However, it may only be optimal for detecting early changes in interstitial fluid rather than late-stage lymphedema. The Perometer is an accurate and reliable instrument, and its use in quantifying limb volume has been well documented (Jain, Danoff, & Paul, 2010; Stanton, Northfield, Holroyd, Mortimer, & Levick, 1997). It uses a sliding frame that emits infrared light to measure arm circumference and length at increments of 0.5 cm. Accompanying software then converts these measurements to overall arm volume. In this study, three measurements were performed on each arm, and the median arm volume of each arm was used as the final measurement. The Perometer is also suitable for a busy clinical setting in which a large volume of women can be measured each day. Of note, the Perometer is an expensive and large device that must be operated by a properly trained individual.

In this study, Perometer arm volume measurements were obtained preoperatively and every three to eight months after surgery. These measurements were performed by one of two trained clinical research coordinators. This postoperative monitoring schedule is unique and more frequent than that used by many other lymphedema studies. Three measurements were performed on each arm at each visit, and the median was used as the final arm volume. The Perometer was regularly calibrated to ensure valid and reliable measurements.

Lymphedema was quantified according to the relative volume change (RVC) equation, which calculates relative change in arm volume compared to the preoperative assessment and accounts for change in size of the contralateral arm as a control (Ancukiewicz et al., 2011). Briefly, RVC = $[(A_2U_1)/(U_2A_1) - 1]$, where A_1 and A_2 are arm volumes on the side of breast cancer at preoperative assessment and postoperative follow-up, and U_1 and U_2 are arm volumes on the contralateral side at the corresponding time points.

Lymphedema was defined as a Perometer measurement of RVC of 10% or greater based on consensus within the literature (Armer & Stewart, 2010; DiSipio, Rye, Newman, & Hayes, 2013). Previous studies have suggested a 5% threshold as being associated with a significant increase in symptoms and change in QOL (Cormier et al., 2009) and an appropriate threshold for mild lymphedema (Stout Gergich et al., 2008). In an analysis by Specht et al. (2013), the authors found that an RVC of 5% to less than 10% occurring more than three months after surgery is significantly associated with an increased risk of progression to an RVC of 10% or greater. Consequently, an assessment with RVC of 5% to less than 10% was also used in the current analysis as a potential indicator of low-level swelling (Cormier et al., 2009). All participants were informed of any increases in arm volume at the time of their follow-up assessments. Women who were found to have lymphedema or symptoms of lymphedema were referred to a credentialed lymphedema physical therapist for follow-up assessment and management.

Fear of Developing or Worsening Existing Lymphedema

The fear-avoidance section of the LEFT-BC includes six statements derived from the previously validated

Survey of Arm Care Following Breast Cancer (Lee et al., 2007) that evaluated lymphedema perceptions and fear-avoidance beliefs and behaviors. Women were asked to rate their level of agreement with each of the six statements either on an electronic survey during the time of their visit or by completing and sending back a hard copy survey within two weeks. Responses were scored using a four-point Likert-type scale, with 4 being strongly agree and 1 being strongly disagree, with an option of "don't know." "Don't know" and unrated statements were excluded. The statements are as follows.

- Having arm swelling would or does significantly change my lifestyle.
- The possibility of developing arm swelling or making it worse worries me.
- Doing strenuous activities with my arms puts me at risk of developing arm swelling or making it worse.
- I plan to avoid strenuous arm activities.
- I am more careful with my arms now than I was before my breast cancer treatment.
- I do not protect my arms in any way. (Scoring was reversed for consistency.)

Data Analysis

Women with and without lymphedema, as defined by RVC greater than or equal to 10%, were included in this analysis to investigate the relationship between the quantitative measure of arm volume change and fear of lymphedema. For each participant, a composite fear score (range = 1–4) was calculated for each screening assessment by summing the scored ratings of the six statements, with a higher score representing greater fear. The total score was divided by

Table 1. Sample Characteristics and Postoperative Fear Score (N = 324)

Characteristic	n	%	$\bar{X}$ Fear Score	95% CI	p
Age at diagnosis (years)					
50 or older	112	35	2.66	[2.57, 2.75]	–
Younger than 50	212	65	2.41	[2.34, 2.48]	< 0.0001
BMI at diagnosis (km/m²)[a]					
Less than 25	126	39	2.52	[2.43, 2.61]	–
25–29.9	117	36	2.5	[2.41, 2.6]	0.796
30 or more	80	25	2.49	[2.38, 2.6]	0.683
Occupation summary MET value					
2.4 (median) or less	155	48	2.51	[2.43, 2.59]	–
Greater than 2.4	169	52	2.5	[2.42, 2.58]	0.891
Family history of breast cancer					
Yes	187	58	2.49	[2.42, 2.57]	0.524
No	137	42	2.53	[2.44, 2.62]	–
Married					
Yes	243	75	2.53	[2.46, 2.59]	0.237
No	81	25	2.45	[2.33, 2.56]	–
At-risk arm is dominant[b]					
Yes	168	52	2.5	[2.42, 2.58]	0.893
No	153	47	2.51	[2.43, 2.59]	–
Breast surgery					
Lumpectomy	242	75	2.46	[2.39, 2.52]	–
Mastectomy	82	25	2.65	[2.54, 2.76]	0.003
Axillary surgery					
SLNB	226	70	2.41	[2.34, 2.47]	0.62[d]
ALND	70	22	2.84	[2.73, 2.95]	< 0.0001[e]
None	28	8	2.46	[2.27, 2.64]	–
Positive lymph nodes					
No	238	73	2.44	[2.37, 2.5]	–
Yes	86	27	2.7	[2.59, 2.81]	< 0.0001
Reconstructive surgery[c] **(N = 82)**					
Yes	56	68	2.68	[2.55, 2.81]	0.487
No	26	32	2.6	[2.41, 2.79]	–
Neoadjuvant chemotherapy					
No	300	93	2.5	[2.44, 2.56]	–
Yes	24	7	2.61	[2.4, 2.82]	0.327
Adjuvant chemotherapy					
No	211	65	2.54	[2.48, 2.6]	–
Yes	113	35	2.43	[2.35, 2.51]	0.002
Radiation therapy					
Breast and chest wall only	208	64	2.39	[2.32, 2.45]	< 0.0001
Breast and chest wall and RLNR	70	22	2.52	[2.44, 2.61]	0.004
None	46	14	2.63	[2.57, 2.7]	–
Hormone therapy					
Yes	261	81	2.5	[2.44, 2.57]	0.855
No	63	19	2.52	[2.39, 2.65]	–

(Continued on the next page)

[a] BMI unknown for one patient

[b] Arm dominance unknown for three patients

[c] Only accounts for patients who underwent a mastectomy

[d] No reference group

[e] SLNB is reference group. When no reference group, p = 0.0005

ALND—axillary lymph node dissection; BMI—body mass index; CI—confidence interval; diff—difference; MET—metabolic equivalent; RLNR—regional lymph node radiation; SLNB—sentinel lymph node biopsy

Table 1. Sample Characteristics and Postoperative Fear Score (N = 324) *(Continued)*

Characteristic	n	%	$\bar{X}$ Fear Score	95% CI	p
Relative arm volume change (%)					
Less than 5	232	72	2.51	[2.45, 2.56]	–
5–10	72	22	2.53	[2.44, 2.62]	0.521
10 or greater	20	6	2.49	[2.35, 2.63]	0.809

Characteristic	Median	Range	$\bar{X}$ Diff in Fear Score	95% CI	p
Postoperative follow-up time (months)	15	6–37	–0.014	[–0.016, –0.011]	< 0.0001
Preoperative fear score	2.7	1–4	0.365	[0.27, 0.46]	< 0.0001

[a] BMI unknown for one patient

[b] Arm dominance unknown for three patients

[c] Only accounts for patients who underwent a mastectomy

[d] No reference group

[e] SLNB is reference group. When no reference group, p = 0.0005

ALND—axillary lymph node dissection; BMI—body mass index; CI—confidence interval; diff—difference; MET—metabolic equivalent; RLNR—regional lymph node radiation; SLNB—sentinel lymph node biopsy

the number of statements rated by the participant to account for statements left unrated and those rated as "don't know." Each of these visit-specific scores was used to calculate the overall mean postoperative fear score across all participants and all postoperative visits. In a similar manner, the authors calculated mean postoperative fear scores within specific subgroups and how mean postoperative fear score changed during the follow-up period at three-month time intervals and by axillary surgery type.

Univariate and multivariate linear mixed effects regression models were used to identify factors associated with mean postoperative fear score or mean difference in postoperative fear score. Mean difference in postoperative fear score represents how the mean fear score was different (on average) for different participant subgroups when controlling for (or adjusting for) other factors that affect fear score. For this analysis, $p < 0.05$ indicated statistical significance. Mixed effects models included a random intercept and accounted for the correlation associated with including multiple measurements from each participant. For continuous variables, such as the amount of postoperative follow-up time at each assessment, quadratic terms were included to assess whether the relationship with fear score was nonlinear. Two-way interaction terms were evaluated for variables that were significant in the multivariate model. The final multivariate model was used to estimate and plot the average postoperative fear score over time within subgroups defined by treatment factors, and other variables were held constant at their mean values. In addition, linear regression was used to identify factors associated with preoperative fear score.

Results

Cohort Characteristics

Three-hundred and twenty-four women met eligibility criteria for this analysis. The demographic and treatment characteristics of the women are listed in Table 1. The median duration of postoperative follow-up among all participants was 15 months (range = 6–37), with a median of four postoperative assessments per participant (range = 1–22). The questionnaire response rate was 94% (1,813 completed questionnaires among 1,937 total assessments). After calculating each participant's composite fear score at each postoperative visit, the mean postoperative fear score across all participants, encompassing all postoperative measurement points, was 2.54 (range = 1–4). The incidence of lymphedema in this cohort during the study period was 6% (n = 20).

Factors Associated With Fear of Developing or Worsening Existing Lymphedema

Univariate results for association of demographic and treatment factors with mean postoperative fear score are listed in Table 1. The mean postoperative fear score was significantly higher for women who underwent axillary lymph node dissection (ALND) (score = 2.84, 95% confidence interval [CI] [2.73, 2.95]) compared with sentinel lymph node biopsy (SLNB) (score = 2.41, 95% CI [2.34, 2.47], $p < 0.0001$). However, women who underwent SLNB reported similar fear scores (score = 2.41, 95% CI [2.34, 2.47]) compared to those with no axillary surgery (score = 2.46, 95% CI [2.27, 2.64], $p = 0.62$).

By univariate analysis, the mean postoperative fear score was significantly higher for women who were younger than age 50 years at the time of their breast cancer diagnosis (score = 2.66, 95% CI [2.57, 2.75]) compared with those who were older than age 50 years (score = 2.41, 95% CI [2.34, 2.48], $p < 0.0001$). The mean postoperative fear score was also significantly higher for women who underwent a mastectomy (score = 2.65, 95% CI [2.54, 2.76]) compared with those who underwent a lumpectomy (score = 2.46, 95% CI [2.39, 2.52], $p = 0.003$). The mean postoperative fear score

was significantly lower in survivors who received adjuvant chemotherapy (score = 2.43, 95% CI [2.35, 2.51]) compared with those who did not (score = 2.54, 95% CI [2.48, 2.6], p = 0.002), as well as for survivors who received radiation to the breast and chest wall only (score = 2.39, 95% CI [2.32, 2.45]) and to the regional lymph nodes (score = 2.52, 95% CI [2.44, 2.61]) compared with those who did not receive any radiation (score = 2.63, 95% CI [2.57, 2.7], p < 0.0001 and p = 0.004, respectively). In addition, a higher mean postoperative fear score was significantly associated with shorter postoperative follow-up time (p < 0.0001) and a higher mean preoperative fear score (p < 0.0001).

Developing lymphedema (RVC of 10% or greater) was not significantly associated with a higher mean postoperative fear score (p = 0.809). Mean postoperative fear score was not significantly different for women with a preoperative body mass index (BMI) of 25–29.9 or a BMI of 30 or greater compared to a BMI of less than 25 (p = 0.796 and p = 0.683, respectively), or significantly associated with having a family history of breast cancer (p = 0.524).

By multivariate analysis, higher preoperative fear score (p < 0.0001), younger age at diagnosis (p = 0.0001), and having undergone ALND (p < 0.0001) were significantly associated with higher mean postoperative fear score (see Table 2). The mean difference in fear score represents how the mean fear score was different (on average) for different participant subgroups, when controlling for (or adjusting for) other factors that affect fear score. For example, women who were older than age 50 years at diagnosis had a fear score that was, on average, 0.204 lower than women who were diagnosed younger than age 50 years, after adjusting for the effects of follow-up time, preoperative fear score, and ALND. Similarly, women who underwent ALND had a fear score that was 0.394 higher, on average, than those who did not undergo ALND, and this difference controls for the other factors in the table.

No significant two-way interactions were found between variables that were significant in the multivariate model. Fear score changed subtly but significantly during the postoperative follow-up period (p < 0.0001), demonstrating a nonlinear temporal pattern. The average postoperative fear score decreased slowly until about 24 months postsurgery, with a very subtle increase thereafter. Figure 1 shows the actual and estimated average postoperative mean fear score over follow-up time by axillary surgery type, with actual mean fear scores calculated within three-month intervals and estimated mean fear scores calculated using the multivariate regression model and substituting the average values for age at diagnosis and preoperative fear score.

Table 3 shows univariate results for factors associated with mean preoperative fear score. No significant difference was found in mean preoperative fear score among BMI categories (p = 0.64 and p = 0.983 for a BMI of 25–29.9 and a BMI of 30 or greater, respectively, compared with a BMI of less than 25), marital status (p = 0.437), occupation summary MET value (p = 0.766), hand dominance (p = 0.369), or age at breast cancer diagnosis (p = 0.317). In addition, family history of breast cancer was not significantly associated with mean preoperative fear score (p = 0.145).

Table 2. Multivariate Results for Factors Associated With Mean Postoperative Fear Score

Variable	$\bar{X}$ Fear Score (95% CI)	p
Postoperative follow-up time (months)	Nonlinear[a]	< 0.0001
Preoperative fear score	0.347 [0.26, 0.435]	< 0.0001
Age at diagnosis (years)		
50 or older	–	–
Younger than 50	–0.204 [–0.309, –0.099]	0.0001
ALND		
No (SLNB or none)	–	–
Yes	0.394 [0.269, 0.52]	< 0.0001

[a] Mode includes significant linear and quadratic terms for postoperative follow-up (p < 0.0001 for both).

ALND—axillary lymph node dissection; CI—confidence interval; SLNB—sentinel lymph node biopsy

Discussion

The authors' data suggest that specific demographic and treatment factors are associated with greater fear of lymphedema, including higher preoperative fear score, younger age at diagnosis, and having undergone ALND. Fear of lymphedema changed subtly but significantly during postoperative follow-up, decreasing until about 24 months postsurgery and leveling thereafter. Identification of factors that contribute to greater fear of developing or worsening existing lymphedema may enable individualized education to reduce fear and potentially improve QOL.

In this study, women who developed lymphedema did not have a significantly higher mean postoperative fear score compared to women without lymphedema by multivariate analysis. This finding suggests that the possibility of developing lymphedema may cause as much or greater fear than the potential of worsening an edema that already exists. Collins et al. (2004) conducted a study of 24 women treated for breast cancer who were recruited to a discussion group that focused on their experiences of physical difficulties, follow-up support, lymphedema, and exercise therapy throughout recovery. Most women reported that lymphedema was a "distressing threat" (Collins

et al., 2004, p. 110). Other studies have reported that lymphedema is a feared long-term complication of breast cancer treatment (Erickson et al., 2001; Lee et al., 2009; McLaughlin et al., 2013; Sander et al., 2012). Thus, lymphedema can be a source of distress for many survivors, affecting even those who have not yet developed the condition.

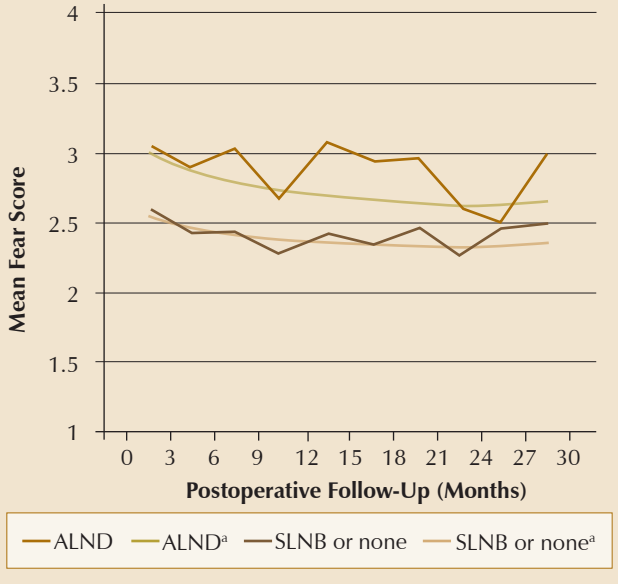
In the authors' study, higher preoperative fear score was significantly associated with higher mean postoperative fear score, suggesting that women with greater fear of developing lymphedema prior to breast cancer treatment remain fearful of the condition after surgery. The authors hypothesize that screening and providing lymphedema education to women with breast cancer before and frequently throughout their cancer treatment may be a psychosocial intervention that could have alerted participants to the possibility of developing lymphedema. This, in conjunction with the possibility that the women may have sought additional information from the Internet where images are readily available, may have created fear in some participants. The authors also considered the possibility that women with higher fear scores may be those who personally know someone who developed lymphedema; however, family history of breast cancer was not associated with a higher preoperative fear score, likely because family history of breast cancer does not accurately account for all of a survivor's previous experience with lymphedema. Analysis of other demographic factors including preoperative BMI, marital status, occupation summary MET value, arm dominance, and age at breast cancer diagnosis did not reveal a significant association with preoperative fear score. Given evidence suggesting a lack of awareness of lymphedema among women with breast cancer and healthcare professionals (Bosompra et al., 2002; Greenslade & House, 2006; Kwan et al., 2012; Lee et al., 2001; Paskett & Stark, 2000; Radina et al., 2004; Tam et al., 2012; Thomas-MacLean et al., 2005), it is more likely that prescreening and providing lymphedema education through the consent process of this study increased fear in some patients before cancer treatment. Given the association of higher preoperative fear score with greater fear of lymphedema postoperatively, the authors suggest that healthcare providers initiate lymphedema education prior to breast cancer treatment in an effort to improve long-term QOL.

ALND is perhaps the most commonly known and consistently reported risk factor for lymphedema (Ashikaga et al., 2010; Bevilacqua et al., 2012; Specht et al., 2013; Tsai et al., 2009). Women in the current cohort who underwent ALND had a significantly higher mean postoperative fear score compared to those who underwent SLNB or no axillary surgery. These findings are consistent with a study by McLaughlin et al. (2013), in which persistent worry about lymphedema was reported for 75% of women who underwent ALND and for 50% of women who underwent SLNB at a 12-month follow-up (McLaughlin et al., 2013). In the current

Table 3. Univariate Results for Factors Associated With Mean Preoperative Fear Score

Variable	$\bar{X}$ Fear Score (95% CI)	p
BMI at diagnosis (km/m²)		
Less than 25	2.69 [2.58, 2.79]	–
25–29.9	2.72 [2.61, 2.84]	0.64
30 or more	2.69 [2.55, 2.76]	0.983
Married		
No	2.75 [2.61, 2.88]	–
Yes	2.68 [2.61, 2.76]	0.437
Occupation summary MET value		
2.4 (median) or less	2.71 [2.62, 2.8]	0.766
Greater than 2.4	2.69 [2.59, 2.79]	–
At-risk arm is dominant		
No	2.67 [2.58, 2.77]	–
Yes	2.74 [2.64, 2.83]	0.369
Family history of breast cancer		
No	2.76 [2.65, 2.87]	–
Yes	2.66 [2.57, 2.75]	0.145
Age at diagnosis (years)		
50 or older	2.67 [2.59, 2.76]	0.317
Younger than 50	2.75 [2.64, 2.87]	–

BMI—body mass index; CI—confidence interval; MET—metabolic equivalent



[a] Estimated mean fear scores; calculated using the multivariate regression model with age at diagnosis and preoperative fear score held constant at their mean values

ALND—axillary lymph node dissection; SLNB—sentinel lymph node biopsy

Figure 1. Differences Between the Latent Classes

cohort, the estimated mean postoperative fear score at 12 months was higher for those women who underwent ALND (score = 2.74) compared to those who underwent SLNB and those who did not undergo axillary surgery (score = 2.35). Of note, half of the women who underwent SLNB in McLaughlin et al.'s (2013) cohort worried about the condition. Although the reported incidence of lymphedema following SLNB is relatively low (about 7%–9% following SLNB compared with 13%–14% following ALND) (Ashikaga et al., 2010), patients who undergo SLNB should be educated about the risk of developing lymphedema to ensure optimal treatment, if needed.

Younger age at diagnosis was significantly associated with higher mean postoperative fear score, indicating that lymphedema is of greater concern for younger women. This finding is of interest because no consistent association exists of young age with risk of developing lymphedema (Kwan et al., 2010; Norman et al., 2010; Paskett, Naughton, McCoy, Case, & Abbott, 2007; Soran et al., 2011). A younger woman who does develop lymphedema may have a long lifetime to survive with this condition that has no definitive cure. This notion may likely contribute to that woman's fear of lymphedema. Studies have reported higher cancer-related worry in younger women compared to older women (Costanzo et al., 2007; Mertz et al., 2012). Thus, consistent education regarding risk factors associated with developing lymphedema may help mitigate fear in young women.

Fear of lymphedema changed subtly but significantly during postoperative follow-up, decreasing until about 24 months postsurgery. Although the results suggest a slightly increasing trend in mean postoperative fear score after 24 months, this very subtle increase is unlikely to reflect a clinically important increase in fear of lymphedema. Rather, the authors interpret the findings as indicating that mean fear score persists near the 24-month level as postoperative follow-up continues past the two-year mark. This finding is consistent with other data regarding QOL after treatment for breast cancer. In the first year after diagnosis, many women with breast cancer undergo adjuvant treatment, including chemotherapy and radiation. During this time period, the focus is on completing and then recovering from treatment. The authors postulate that, at 24 months, women become confident in surviving from breast cancer and, therefore, more focused on their QOL. Re-educating survivors of breast cancer about risk of lymphedema at this time may help mitigate unnecessary fears. To the authors' knowledge, this represents the largest series of women screened for fears associated with breast cancer–related lymphedema. The entire cohort of women received standardized lymphedema education prior to initiation of breast cancer treatment. Controlling for lack of knowledge about the condition allowed the authors to evaluate other risk factors associated with postoperative fear of lymphedema. In addition, women were prospectively screened for measured lymphedema and fear avoidance beliefs or behaviors beginning at the preoperative assessment and extending to 24 months postoperative follow-up, which enabled the evaluation of trends in fear throughout the course of breast cancer treatment. Because survivors are at a lifetime risk of developing lymphedema, future studies are needed to follow survivors in the long-term (i.e., after 24 months) with regard to lymphedema development, fear, and preventive care.

Knowledge Translation

Younger breast cancer survivors and those who undergo axillary lymph node dissection exhibit greater fear of developing lymphedema postoperatively.

Greater fear of lymphedema development preoperatively is associated with greater fear of developing lymphedema postsurgery.

Although fear of lymphedema may decrease during the first two years postoperatively, it does so only subtly, and persists past the two-year mark. Thus, evaluating and determining the impact of survivors' fear of lymphedema two years postsurgery may be useful.

Limitations

Several limitations existed in the current study. The low incidence of lymphedema in this cohort (n = 20, 6%) may have diminished the ability to analyze fear of worsening lymphedema once it develops. In terms of study design, instances occurred in which some participants completed the questionnaire at home and returned it within two to three weeks. Thus, a small proportion of patients may have been aware of their arm measurement status prior to completion of the questionnaire, which is a potential source of bias. In addition, responses to the statement, "I am more careful with my arms now than I was before my breast cancer treatment," may not necessarily indicate a concerning level of fear associated with lymphedema. For example, some women may be very careful to maintain skin integrity on the affected arm, reflecting careful health practices rather than exhibiting unreasonable fears.

Several factors may have influenced fears and perceptions about lymphedema that the authors did not include and control for in the study. First, the authors did not measure the native anxiety level of women who participated in this study, potentially leading to an overestimation of their fear with respect to lymphedema. This information would have been helpful in

identifying women who may need more explanation, reassurance, and monitoring to prevent overdiligence with risk-reduction practices, whether proven or not. Second, the duration of the study occurred within the first two postoperative years, a time frame in which the greatest risk of local recurrence is present, but the authors did not measure or control for fears associated with recurrence. This may have confounded the results by overestimating fear of lymphedema. The authors also did not include information about prior exposure to lymphedema, whether through other individuals or other sources of information such as online or through programs. Prior exposure to or knowledge about lymphedema may have increased participants' fear. Finally, the authors did not assess the potential influence of ongoing lymphedema monitoring. Frequent monitoring may have heightened participants' concerns about developing lymphedema.

Implications for Nursing

Lymphedema education should begin preoperatively, continue throughout breast cancer treatment, and be re-emphasized at 24 months postsurgery. Particular attention should be paid to younger patients and those who undergo ALND who, based on the findings, experience greater fear of lymphedema. If and when fear of lymphedema is identified, nurses should evaluate whether that fear generates appropriate proactive behavior to prevent lymphedema or whether it negatively affects the survivor's physical or mental state. In the latter case, such fear should alert nurses to counsel, educate, reassure, support, and reassess the patient on an ongoing basis.

Conclusions

Although the current study helped to identify specific demographic and treatment factors that may contribute to fear of developing or worsening existing lymphedema, many other factors likely influence survivors' fear. The uncertainty of prediction, lack of definitive treatment, and negative impact on QOL are all important factors that may contribute to a patient's fear of developing this condition. Additional studies are needed to explore these factors.

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