

Symptom Frequency, Intensity, and Distress in Patients with Lower Limb Lymphedema

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Background: Patients with lower limb lymphedema experience symptoms of pain, swelling, tightness, and heaviness in their legs. Less is known of the intensity and distress associated with these symptoms. This study sought to identify and compare the symptoms and the level of intensity and distress associated with symptoms by type of lymphatic disruption.

Methods and Results: A cross-sectional design was used. Patients completed an online survey that included: a demographic form, the Lymphedema Symptom Intensity and Distress Survey-Leg, and an open-ended question. The most prevalent symptoms were swelling, concerns about looks, heaviness, tightness, fatigue, and reduced physical activity. Statistically significant differences were found among groups in coldness in legs ($\chi^2_{(df=3)} = 9.0, p=0.03$), lack of confidence in self ($\chi^2_{(df=3)} = 10.6, p=0.014$), and feeling less sexually attractive ($\chi^2_{(df=6)} = 12.6, p=0.049$). Group differences were also observed in the intensity of heaviness ($\chi^2_{(df=3)} = 9.11, p=0.03$), numbness, ($\chi^2_{(df=3)} = 10.66, p=0.014$), achiness ($\chi^2_{(df=3)} = 12.40, p=0.006$), skin flakiness ($\chi^2_{(df=3)} = 13.22, p=0.004$), and lack of interest in sex ($\chi^2_{(df=3)} = 8.95, p=0.030$). Statistically significant group differences were not found in distress related to symptoms.

Conclusions: Despite the number of symptoms reported by patients with lower-limb lymphedema, only a few statistically significant differences in symptoms and level of intensity were observed by type of lymphatic disruption. No statistically significant group differences were found in the distress level associated with any of the symptoms.

Introduction

LYMPHEDEMA REFERS TO THE SWELLING that occurs in a part of the body due to a failure of the lymphatic system to support lymphatic circulation and the drainage of lymphatic fluid.¹⁻³ It is a debilitating, chronic condition with physical, psychological, and social consequences for those diagnosed with the disease.^{4,5}

Lymphedema can be either primary or secondary in nature. Primary lymphedema is a genetic disorder of the lymphatic vessels or lymph nodes,^{6,7} or a dysfunction in the lymphatic system.^{1,8} Primary lymphedema can further be categorized according to the age of symptom onset and clinical manifestation: congenital (before age 2), praecox (between age 2 and 35), and tarda (after age 35).³ Lymphedema involving both lower extremities occurs in about 70% of patients with congenital lymphedema and lymphedema tarda.¹ Lymphedema praecox is typically unilateral with involvement of the foot and the calf, with only 30% of patients developing bilateral extremity lymphedema.^{1,3}

Secondary lymphedema is caused by various factors related to either lymphatic obstruction or lymphatic interruption due to

inflammation, trauma, iatrogenic alterations of the lymph system (i.e., surgery or radiation),³ or due to cancer therapy.^{6,7,9,10} In developing countries, secondary lymphedema is predominantly caused by parasites, while in developed countries it most commonly occurs due to malignancies or malignancy-associated treatments.^{2,3} Secondary lymphedema following cancer and related treatments is seen especially in patients with breast^{11,12} and gynecological malignancies.^{2,13,14} Developing lower limb lymphedema following cancer treatment is associated with several risk factors. Hareyama et al. retrospectively reviewed 358 patients with cervical, endometrial, and ovarian cancer who underwent lymphadenectomy,¹³ and found risk factors for lower limb lymphedema to include the removal of circumflex iliac lymph nodes, cellulitis, and the number of lymph nodes removed. Graf and colleagues similarly identified infection, the number of lymph nodes removed, and the presence of postoperative lymphocysts as risk factors in a retrospective analysis of 313 records of gynecological cancer survivors.¹⁵

Secondary lower limb lymphedema is increasingly recognized as an important long-term complication following genito-urinary cancer treatment.^{5,16} In patients undergoing lymphadenectomy in newly diagnosed gynecological malignancies ($n=293$), the

prevalence of lower limb lymphedema one year after surgery was 32% and increased to 58% eight years after surgery.¹⁵ Similarly, in a group of long-term cancer survivors, 34.5% of patients ($n=37$) reported one or more symptoms of lower limb lymphedema.¹⁷ Patients at increased risk for lower limb lymphedema include patients treated for vulvar, cervical, and ovarian cancer that included the removal of lymph nodes and follow up radiation.^{16,18} Lower limb lymphedema is also seen in males following prostate surgery.¹⁹ Secondary lower limb lymphedema may also occur due to trauma,^{6,20} or following a surgical procedure.²¹

Some patient-reported outcome measures have been used to understand the impact of lower limb lymphedema on patients physical and psychosocial functioning. Examples of these measures include the Lymphoedema Quality-of-Life (LYM-QOL) Study Survey,²² the European Organization for Research and Treatment of Cancer (EORTC) Survey,²³ and the Symptom Distress Scale.²⁴ Patients with a diagnosis of lower limb lymphedema reported the most common physical symptoms as tightness (16%), pain/tenderness (23%), and heaviness (15%).²⁵ They also experience numbness (21%), tingling sensation (15%), warmth or redness (13%),²⁵ and tissue fibrosis and associated skin changes.¹⁴ Decreased physical function, dyspnea, and fatigue occurs frequently in patients with lower limb lymphedema.²³ Nearly a third of patients with lower limb lymphedema experienced three or more physical symptoms,¹⁷ and these symptoms are exacerbated by prolonged standing, heat, and walking.^{16,25}

Patients with lower limb lymphedema also have psychosocial concerns including: decreased social functioning,^{9,23,26} poor body image, low self-esteem, and embarrassment.² In a study of the effects of lower limb lymphedema in gynecological cancer survivors,²⁶ Dunberger and colleagues found that 27% of patients avoided social activities and 20% avoided meeting friends. Unmet supportive care needs including the cost of having lower limb lymphedema, pain/discomfort in legs/groin, and unmet sexual needs.²² Thus, having lower limb lymphedema can significantly impact patients' lives and their daily activities.

Despite these studies, little is known of the intensity and level of distress patients with lower limb lymphedema experience due to their symptoms. Additionally, there is scarce information regarding whether type of lymphedema impacts the symptom profile. Therefore, as part of an ongoing series of instrument development studies, data were collected regarding symptoms related to lower limb lymphedema. This article leveraged data from that study with the purpose of identifying symptoms associated with lower limb lymphedema, and, comparing symptom intensity and distress across lymphedema types.

Materials and Methods

Design

This study employed a cross-sectional design using an on-line accessible survey methodology.

Ethical considerations

Institutional Review Board (IRB) approval was sought for this study from Vanderbilt University, and the study was approved for exempt status. The procedures that were followed for this study were in accordance with the ethical

standards of the responsible conduct of human research and the Helsinki Declaration of 1975, as revised in 2008.

Participants

Volunteers were recruited from flyers posted at the websites of the National Lymphedema Network and the Lymphatic Education and Research Network; through a posting on www.lympdemablog.com; and through a mass e-mail sent to Vanderbilt University faculty and staff. Interested individuals contacted the study office and were screened for eligibility by study staff. Information about the study and risks and benefits associated with participation, as well as the assurance of the confidentiality of participant responses, were provided verbally by study staff who screened patients and on the study website. Only those who met eligibility criteria were enrolled in the study. Recruitment took place from in 2012 from February 8 to September 26. Individuals were eligible for the study if they were 18 years of age or older, could read and speak English, and had been told by a healthcare professional that they had lower limb lymphedema.

Data collection

Volunteers who agreed to participate were provided with a unique, protected access code that enabled them to log into a confidential website, Research Electronic Data Capture program (REDCapTM). Once logged into REDCap, participants completed the web-based survey. The survey consisted of three data collection tools: a demographic form, the Lymphedema Symptom Intensity and Distress Survey-Leg (LSIDS-L), and one open-ended question.

Demographic form. A demographic form was used to gather information on age, gender, race, ethnicity, years of education completed, marital status, income level, employment status, area of residence, and insurance status.

Lymphedema symptom intensity and distress survey-leg. The LSIDS-L is a 36-item, revised version of the Lymphedema Symptom Intensity and Distress Survey-Arm (LSIDS-A). Participants indicated whether a symptom was present ("yes" or "no") and, if "yes", to rate the intensity (the actual severity of the symptom itself) and associated distress (the physical or emotional response to a symptom) on two separate 10-point scales (1 = slight to 10 = severe). Participants who indicated "yes" to swelling in their abdomen, back, or groin completed an additional section of questions. Participants had the option of answering "prefer not to answer" for questions that were of a sensitive nature to the participant (such as relating to feeling less sexually attractive, lack of interest in sex, or partner's lack of interest in sex). The number of items to which a participant responded ranged from a minimum of 46 to a maximum of 177.

Open-ended question. An open-ended question, "Please list any other symptoms or problems related to your legs swelling that we did not ask," was included to afford the participants an opportunity to report any additional symptoms not covered within the 36 structured items. Participants could elect not to answer this question and still be in the study.

Statistical analyses

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 22.0 (Armonk, NY). Survey data were analyzed using descriptive statistics. Inferential statistics conducted include Chi-Square for nominal data and Kruskal-Wallis Tests for not normally distributed data. Fisher test of skewness was used to determine the distribution of the continuous data. Normally distributed data for continuous variables are presented as means (M) and standard deviations (SD) and as medians and interquartile ranges (IQR) when skewed. Data for categorical variables are reported as counts (N) and percentages (%).

Results

Participant characteristics

Three hundred and twenty individuals who contacted the study office and expressed an interest in participating in the study were screened for eligibility. Two-hundred eighty

seven met inclusion criteria and were enrolled; 74% of those enrolled completed the study for a total of 213 participants (Table 1).

Descriptive summaries of patients with lower limb lymphedema by lymphedema type are shown in Table 1. Participants were predominantly female ($n=191$, 90%) and many lived in rural areas ($n=82$, 39%). Four categories of participants by types of lymphedema emerged: primary lymphedema ($n=96$, 45%), secondary cancer-related lymphedema ($n=37$, 17%), secondary non-cancer-related lymphedema ($n=45$, 21%), and lymphedema of unknown causation ($n=35$, 17%). An almost equal number of participants reported lymphedema in one ($n=85$, 40%) or both legs ($n=88$, 42%).

Symptom prevalence

Symptoms that occurred in $\geq 66\%$ of all of the participants with lower limb lymphedema were: swelling ($n=205$, 97.6%), concerns about looks ($n=175$, 82.5%), heaviness ($n=173$, 82%), tightness ($n=169$, 79.7%), fatigue ($n=161$,

TABLE 1. DESCRIPTIVE STATISTICAL SUMMARIES OF STUDY GROUPS

	Cancer N (%)	Secondary non-cancer N (%)	Primary N (%)	Unknown N (%)	Total N (%)	P value*
Total by group	37 (17)	45 (21)	96 (45)	35 (16)	213 (100)	
<i>Gender</i>						0.085
Male	1 (2.7)	3 (6.7)	15 (15.6)	3 (8.6)	22 (10.3)	
Female	36 (97.3)	42 (93.3)	81 (84.4)	32 (91.4)	191 (89.7)	
<i>Race</i>						0.291
White	34 (91.9)	40 (88.9)	80 (83.3)	28 (80.0)	182 (85.4)	
Black	3 (8.1)	2 (4.4)	9 (9.4)	5 (14.3)	19 (8.9)	
Other	0 (0)	3 (6.7)	7 (7.3)	2 (5.7)	12 (5.6)	
<i>Ethnic group</i>						0.291
Hispanic or Latino	3 (8.1)	0 (0)	6 (6.5)	2 (5.7)	11 (5.3)	
Not Hispanic or Latino	34 (91.9)	42 (100)	87 (93.5)	33 (94.3)	196 (94.7)	
<i>Marital status</i>						0.173
Single	8 (21.6)	10 (22.2)	19 (19.8)	14 (40)	51 (23.9)	
Married or Living with partner	27 (72.9)	32 (71.1)	67 (69.8)	18 (51.4)	144 (67.6)	
Widowed	1 (2.7)	3 (6.7)	3 (3.1)	1 (2.9)	8 (3.8)	
Other	1 (2.7)	0 (0)	7 (7.3)	2 (5.7)	10 (4.7)	
<i>Employment status</i>						0.010
Employed full-time	17 (45.9)	17 (37.8)	41 (42.7)	20 (57.1)	95 (44.6)	
Employed part-time	6 (16.2)	9 (20)	9 (9.4)	3 (8.6)	27 (12.7)	
Unemployed	0 (0)	3 (6.7)	12 (12.5)	6 (17.1)	21 (9.9)	
Retired	10 (27)	9 (20)	16 (16.7)	1 (2.9)	36 (16.9)	
Homemaker	0 (0)	4 (8.9)	4 (4.2)	2 (5.7)	10 (4.7)	
<i>Insurance coverage</i>						0.115
Medicare	12 (32.4)	9 (20.5)	17 (18.1)	2 (5.7)	40 (19)	
Medicaid	1 (2.7)	2 (4.5)	6 (6.4)	1 (2.9)	10 (4.8)	
Private insurance	14 (37.8)	17 (38.6)	31 (33.0)	16 (45.7)	78 (37.1)	
HMO	5 (13.5)	4 (9.1)	17 (18.1)	3 (8.6)	29 (13.8)	
None	0 (0)	4 (9.1)	2 (2.1)	2 (5.7)	8 (3.8)	
Other	5 (13.5)	8 (18.2)	21 (22.3)	11 (31.4)	45 (21.4)	
<i>Lymphedema location</i>						0.000
Left leg	11 (29.7)	15 (33.3)	12 (12.5)	11 (32.4)	49 (23.1)	
Right leg	8 (21.6)	11 (24.4)	12 (14.6)	3 (8.8)	36 (17.0)	
Both legs	7 (18.9)	10 (22.2)	55 (57.3)	16 (47.1)	88 (41.5)	
Leg and abdomen/groin	6 (16.2)	2 (4.4)	5 (5.2)	1 (2.9)	14 (6.6)	
Both legs and abdomen/groin	5 (13.5)	7 (15.6)	10 (10.4)	3 (8.8)	25 (11.8)	

*Likelihood Ratio.

TABLE 2. GROUP DIFFERENCES IN PHYSICAL SYMPTOM FREQUENCY

	<i>Cancer</i> N (%)	<i>Secondary non-cancer</i> N (%)	<i>Primary</i> N (%)	<i>Unknown</i> N (%)	<i>Total</i> N (%)	<i>Group differences*</i> (p-values)
Total by Group	37 (17)	45 (21)	96 (45)	35 (16)	213 (100)	
<i>Heaviness</i>						0.233
No	5 (13.2)	6 (15.8)	23 (60.5)	4 (10.5)	38 (18)	
Yes	32 (86.5)	38 (86.4)	73 (76.0)	30 (88.2)	173 (82)	
<i>Tightness</i>						0.419
No	11 (25.6)	7 (16.3)	19 (44.2)	6 (14)	43 (20.3)	
Yes	26 (15.4)	38 (22.5)	77 (45.6)	28 (16.6)	169 (79.7)	
<i>Burning pain</i>						0.849
No	22 (16.2)	29 (21.3)	61 (44.9)	24 (17.6)	136 (64.8)	
Yes	14 (18.9)	15 (20.3)	35 (47.3)	10 (13.5)	74 (35.2)	
<i>Stabbing pain</i>						0.819
No	26 (16.6)	32 (20.4)	71 (45.2)	28 (17.8)	157 (74.4)	
Yes	10 (18.5)	13 (24.1)	24 (44.4)	7 (13.0)	54 (25.6)	
<i>Cramping</i>						0.958
No	24 (18.5)	28 (21.5)	56 (43.1)	22 (16.9)	130 (62.2)	
Yes	13 (16.5)	16 (20.3)	37 (46.8)	13 (16.5)	79 (37.8)	
<i>Pain in legs</i>						0.064
No	22 (22.2)	23 (23.2)	42 (42.4)	12 (12.1)	99 (47.1)	
Yes	12 (10.8)	22 (19.8)	54 (48.6)	23 (20.7)	111 (52.9)	
<i>Warmth</i>						0.640
No	23 (17.2)	25 (18.7)	64 (47.8)	22 (16.4)	134 (64.1)	
Yes	13 (17.3)	19 (25.3)	30 (40)	13 (17.3)	75 (35.9)	
<i>Coldness in legs</i>						0.029
No	34 (20.2)	33 (19.6)	77 (45.8)	24 (14.3)	168 (80.0)	
Yes	2 (4.8)	12 (28.6)	17 (40.5)	11 (26.2)	42 (20.0)	
<i>Numbness</i>						0.238
No	20 (14.5)	25 (18.1)	70 (50.7)	23 (16.7)	138 (67.0)	
Yes	15 (22.1)	17 (25)	26 (38.2)	10 (14.7)	68 (33.0)	
<i>Achiness</i>						0.745
No	13 (16.0)	16 (19.8)	40 (49.4)	12 (14.8)	81 (38.9)	
Yes	22 (17.3)	29 (22.8)	53 (41.7)	23 (18.1)	127 (61.1)	
<i>Swelling</i>						0.175
No	1 (20)	2 (40)	0 (0)	2 (40)	5 (2.4)	
Yes	35 (17.1)	43 (21.0)	95 (46.3)	32 (15.6)	205 (97.6)	
<i>Hardness</i>						0.746
No	14 (18.2)	16 (20.8)	32 (41.6)	15 (19.5)	77 (37.2)	
Yes	21 (16.2)	28 (21.5)	62 (47.7)	19 (14.6)	130 (62.8)	
<i>Tingling</i>						0.456
No	25 (16.9)	27 (18.2)	71 (48.0)	25 (16.9)	148 (71.2)	
Yes	9 (15.0)	17 (28.3)	25 (41.7)	9 (15.0)	60 (28.8)	
<i>Pins and needles</i>						0.894
No	26 (17.4)	30 (20.1)	67 (45.0)	26 (17.4)	149 (70.6)	
Yes	10 (16.1)	15 (24.2)	28 (45.2)	9 (14.5)	62 (29.4)	
<i>Difficulty moving</i>						0.666
No	30 (19.4)	33 (21.3)	67 (43.2)	25 (16.1)	155 (73.1)	
Yes	7 (12.3)	12 (21.1)	28 (49.1)	10 (17.5)	57 (26.9)	
<i>Difficulty raising legs</i>						0.986
No	22 (18.0)	25 (20.5)	56 (45.9)	19 (15.6)	122 (57.8)	
Yes	15 (16.9)	20 (22.5)	40 (44.9)	14 (15.7)	89 (42.2)	
<i>Difficulty standing</i>						0.100
No	28 (22.6)	24 (19.4)	55 (44.4)	17 (13.7)	124 (58.5)	
Yes	9 (10.2)	20 (22.7)	41 (46.6)	18 (20.5)	88 (41.5)	
<i>Skin flakiness</i>						0.148
No	28 (22.4)	26 (20.8)	52 (41.6)	19 (15.2)	125 (59.0)	
Yes	9 (10.3)	19 (21.8)	44 (50.6)	15 (17.2)	87 (41.0)	
<i>Sadness</i>						0.187
No	14 (21.2)	17 (25.8)	29 (43.9)	6 (9.1)	66 (31.4)	
Yes	22 (15.3)	28 (19.4)	66 (45.8)	28 (19.7)	144 (68.6)	

(continued)

TABLE 2. (CONTINUED)

	Cancer N (%)	Secondary non-cancer N (%)	Primary N (%)	Unknown N (%)	Total N (%)	Group differences* (p-values)
<i>Anger</i>						0.829
No	20 (18.0)	22 (19.8)	53 (47.7)	16 (14.4)	111 (52.9)	
Yes	17 (17.2)	23 (23.2)	42 (42.4)	17 (17.2)	99 (47.1)	
<i>Lack of self-confidence</i>						0.014
No	25 (26.6)	16 (17.0)	41 (43.6)	12 (12.8)	94 (44.8)	
Yes	12 (10.3)	29 (25.0)	53 (45.7)	22 (19.0)	116 (55.2)	
<i>Lack of confidence in insurance</i>						0.956
No	19 (16.1)	25 (21.2)	55 (46.6)	19 (16.1)	118 (57.0)	
Yes	17 (19.1)	18 (20.2)	40 (44.9)	14 (15.7)	89 (43.0)	
<i>Concerns about looks</i>						0.408
No	10 (27.0)	7 (18.9)	15 (40.5)	5 (13.5)	37 (17.5)	
Yes	27 (15.4)	38 (21.7)	80 (45.7)	30 (17.1)	175 (82.5)	
<i>Misunderstood by S.O.</i>						0.179
No	30 (20.0)	30 (20.0)	62 (41.3)	28 (18.7)	150 (71.1)	
Yes	7 (11.5)	14 (23.0)	33 (54.1)	7 (11.5)	61 (28.9)	
<i>Less sexually attractive</i>						0.049
No	14 (23.7)	7 (11.9)	32 (54.2)	6 (10.2)	59 (28.0)	
Yes	16 (13.8)	30 (25.9)	46 (39.7)	24 (20.7)	116 (55.0)	
Prefer not to answer	6 (16.7)	8 (22.2)	17 (47.2)	5 (13.9)	36 (17.1)	
<i>Insurance frustration</i>						0.516
No	24 (19.0)	23 (18.3)	56 (44.4)	23 (18.3)	126 (60.0)	
Yes	12 (14.3)	21 (25.0)	39 (46.4)	12 (14.3)	84 (40.0)	
<i>Lost body confidence</i>						0.611
No	15 (21.7)	12 (17.4)	30 (43.5)	12 (17.4)	69 (32.7)	
Yes	22 (15.5)	32 (22.5)	66 (46.5)	22 (15.5)	142 (67.3)	
<i>Fatigue</i>						0.377
No	12 (23.5)	7 (13.7)	24 (47.1)	8 (15.7)	51 (24.1)	
Yes	25 (15.5)	37 (23.0)	72 (44.7)	27 (16.8)	161 (75.9)	
<i>Difficulty sleeping</i>						0.352
No	20 (19.0)	17 (16.2)	49 (46.7)	19 (18.1)	105 (49.5)	
Yes	17 (15.9)	28 (26.2)	46 (43.0)	16 (15.0)	107 (50.5)	
<i>Increased appetite</i>						0.892
No	27 (17.1)	32 (20.3)	74 (46.8)	25 (15.8)	158 (74.9)	
Yes	9 (17.0)	13 (24.5)	22 (41.5)	9 (17.0)	53 (25.1)	
<i>Lack interest in sex</i>						0.264
No	15 (14.6)	17 (16.5)	48 (46.6)	23 (22.3)	103 (49.0)	
Yes	15 (21.4)	18 (25.7)	30 (42.9)	7 (20.0)	70 (33.3)	
Prefer not to answer	5 (13.5)	9 (24.3)	18 (48.6)	5 (13.5)	37 (17.6)	
<i>Partner lack of interest in sex</i>						0.856
No	23 (18.4)	27 (21.6)	52 (41.6)	23 (18.4)	125 (60.1)	
Yes	5 (15.2)	8 (24.2)	16 (48.5)	4 (12.1)	33 (15.9)	
Prefer not to answer	8 (16.0)	10 (20.0)	26 (52.0)	6 (12.0)	50 (24.0)	
<i>Can't do hobbies or leisure activities</i>						0.773
No	14 (19.2)	13 (17.8)	35 (47.9)	11 (15.1)	73 (34.3)	
Yes	23 (16.4)	32 (22.9)	61 (43.6)	24 (17.1)	140 (65.7)	
<i>Less social activities</i>						.309
No	23 (21.7)	22 (20.8)	47 (44.3)	14 (13.2)	106 (50.2)	
Yes	14 (13.3)	22 (21.0)	48 (45.7)	21 (20.0)	105 (49.8)	
<i>Less physical activity</i>						0.706
No	12 (19.0)	11 (17.5)	31 (49.2)	9 (14.3)	63 (29.7)	
Yes	24 (16.1)	34 (22.8)	65 (43.6)	26 (17.4)	149 (7.3)	
<i>0</i>						0.800
No	14 (15.4)	16 (17.6)	43 (47.3)	18 (19.8)	91 (43.5)	
Yes	13 (18.1)	18 (25.0)	32 (44.4)	9 (12.5)	72 (34.4)	
Prefer not to answer	8 (17.4)	11 (23.9)	21 (45.7)	6 (13.0)	46 (22.0)	

75.9%), less physical activity ($n=149$, 70.3%), sadness ($n=144$, 68.6%), and loss of body confidence ($n=142$, 67.3%). In addition, $\geq 66\%$ of participants with primary lower limb lymphedema reported hardness ($n=62$, 66%), and $\geq 66\%$ of participants with secondary non-cancer-related lower limb lymphedema reported loss of body confidence ($n=32$, 72.7%), inability to complete hobbies ($n=32$, 71.1%), and being less sexually active ($n=30$, 66.7%).

Statistically significant differences were found among the groups in coldness in legs ($\chi^2_{(df=3)}=9.0$, $p=0.03$), lack of confidence in self ($\chi^2_{(df=3)}=10.6$, $p=0.014$), and feeling less sexually attractive ($\chi^2_{(df=6)}=12.6$, $p=0.049$). The cancer group had fewer participants experiencing coldness, lack of confidence in self, and feeling less sexually attractive than any of the other groups (Table 2).

Symptom intensity

Overall symptom intensity scores are shown in Table 3. Highest intensity symptoms included: insurance frustration, less socially active, loss of body confidence, lack of sexual interest, lack of confidence in insurance, inability to do hobbies or leisure activities, and feeling less sexually attractive. Compared to other groups, except for concerns about looks (Median=9.0, IQR=5,10), the cancer group had lower median intensity scores for symptoms with the highest prevalence (Table 4).

Statistically significant differences among the groups were observed in intensity of heaviness in legs ($\chi^2_{(df=3)}=9.11$, $p=0.03$), numbness in legs ($\chi^2_{(df=3)}=10.66$, $p=0.014$), achiness in legs ($\chi^2_{(df=3)}=12.40$, $p=0.006$), skin flakiness on legs ($\chi^2_{(df=3)}=13.22$, $p=0.004$) and lack of sexual interest ($\chi^2_{(df=3)}=8.95$, $p=0.030$). Post-hoc analyses using Oneway ANOVA Sheffe tests revealed that patients with secondary lower limb lymphedema in the cancer group had a lower intensity of numbness in their legs ($N=15$, $M=22.9$, $SD=20.41$) compared to patients with secondary lower limb lymphedema in the non-cancer group ($N=17$, $M=42.5$, $SD=18.43$). Patients in the cancer group also experienced less achiness in their legs ($N=22$, $M=44.1$, $SD=41.27$) compared to the patients in the unknown group ($N=29$, $M=66.48$, $SD=36.03$) and less intensity in skin flakiness in their legs ($N=9$, $M=20.17$, $SD=17.32$) compared to those with primary lower limb lymphedema ($N=19$, $M=46.05$, $SD=25.92$). No other statistically significant differences were observed between the groups.

Symptom distress

Overall symptom prevalence and distress scores are reflected in Table 3. The highest distress median score of 9.0 were reported for insurance frustration and lack of confidence in insurance. Median distress scores of 8.0 were also reported for swelling, appearance concerns, less physical activity, loss of body confidence, inability to do hobbies or leisure activities, increased appetite, lack of self-confidence, and feeling less sexually attractive. Except for concerns about looks and loss of body confidence, participants in the cancer group reported lower distress scores for symptoms with the highest prevalence (Table 4).

The only statistically significant difference found among groups was patients' distress related to heaviness in their legs ($\chi^2_{(df=3)}=8.95$, $p=0.030$). Post-hoc analyses using Oneway

ANOVA Sheffe tests revealed that only 5% of the variability in patients' distress due to heaviness in their legs could be accounted for by the type of lymphedema. However, no statistically significant differences were observed between the four groups of patients with distress due to heaviness in their legs.

Discussion

The six most common symptoms experienced by individuals with lower limb lymphedema are similar to known upper limb lymphedema symptoms; however, intensity and distress scores were higher in these participants.¹² Patients in this study reported symptoms that fall in either the physical or psychosocial domains. The most common physical symptoms reported included swelling, heaviness, tightness, and fatigue. In contrast to other studies of patients with lower limb lymphedema that have reported the presence of swelling, tightness, and heaviness in 13% to 25% of patients,^{16,23,25,27} the majority of patients in this study ($\geq 66\%$) reported the presence of these symptoms.

The findings of this study also support other reports that patients with lower limb lymphedema experience fatigue,²³ however, this study demonstrates a high prevalence of fatigue ($\geq 75\%$) among patients with lower limb lymphedema. Pain is another symptom others have reported as a common symptom. Although it was not one of the most prevalent symptoms reported in this study, the majority of patients ($\geq 50\%$) experienced pain. This finding is in contrast to one previous report of only 23% of patients experiencing pain.²⁵ One potential reason for the difference in these findings is the inclusion of patients with limb swelling with or without a diagnoses of lymphedema by a healthcare professional in the earlier study,²⁵ whereas this study included only patients who reported a confirmed diagnosis of lymphedema by a healthcare professional.

More than two-thirds of patients in this study reported also psychosocial symptoms including: concerns about looks, decreased physical activity, and sadness. Additional psychosocial symptoms reported by more than 50% of participants include the inability to do hobbies or leisure activities, a lack of self-confidence, and feeling less sexually attractive. These findings mirror other reports of patients experiencing challenges in the psychological and social domains of their lives.^{23,26}

The majority of patients in this study reported the presence of psychosocial symptoms. This is in contrast to previous reports of psychosocial symptoms being present in 20%–27% of patients. These studies, however, examined lower limb lymphedema in patients following treatment for gynecologic malignancies, whereas the current compared patients with primary and secondary (cancer- and non-cancer-related) lower limb lymphedema. Thus, the psychosocial impact of lower limb lymphedema extends well beyond those with cancer-related lower limb lymphedema.

This study found that patients with lower limb lymphedema experience a higher level of intensity in the psychosocial domains rather than the physical domains. Specifically, participants reported the highest symptom intensity in the areas of insurance, appearance and body confidence, and sexuality. In several studies, patients with lower limb lymphedema reported feeling less attractive as women, with patients reporting avoiding social activities (27%) and

TABLE 3. DESCRIPTIVES FOR SYMPTOM INTENSITY AND DISTRESS

<i>Symptom</i>	<i>Symptom prevalence % (Overall)</i>	<i>Symptom Intensity Median [IQR;Min,Max]</i>	<i>Symptom Distress Median [IQR; Min,Max]</i>
Swelling	97.6	7.0 [5,9; 1,10]	8.0 [4,9; 1,10]
Concerns about looks	82.5	8.0 [5.25,10; 1,10]	8.0 [5,8; 1,10]
Heaviness*	82.0	6.0 [4,8; 1,10]*	7.0 [4,9; 1,10]*
Tightness	79.7	6.0 [5,8; 1,10]	7.0 [4,8; 1,10]
Fatigue	75.9	7.0 [5,8; 1,10]	7.0 [4.25,8; 1,10]
Less physical activity	70.3	7.0 [5,9; 1,10]	8.0 [5,10; 1,10]
Sadness	68.6	6.0 [4,9; 1,10]	7.0 [4,9; 1,10]
Lost body confidence	67.3	8.0 [6,9; 1,10]	8.0 [6,10; 1,10]
Can't do hobby or leisure activities	65.7	8.0 [5.75,10; 1,10]	8.0 [6,10; 1,10]
Hardness	62.8	6.0 [4,8; 1,10]	7.0 [3.5,9; 1,10]
Achiness**	61.1	6.0 [4,8; 1,10]**	5.0 [3,8; 1,10]
Lack of self-confidence	55.2	7.0 [5,9; 1,10]	8.0 [5,10; 1,10]
Less sexually attractive	55.0	8.0 [5,10; 1,10]	8.0 [5,10; 1,10]
Pain	52.9	6.0 [4,8; 1,10]	6.0 [4,8; 1,10]
Difficulty sleeping	50.5	7.0 [5,8; 1,10]	7.0 [5,9; 1,10]
Less social activity	49.8	8.0 [7,10; 1,10]	8.0 [7,10; 1,10]
Anger	47.1	6.0 [4,8; 1,10]	6.0 [4,8; 1,10]
Lack of confidence in insurance	43.0	8.0 [6,10; 1,10]	9.0 [7,10; 1,10]
Raising difficulty	42.2	7.0 [5,8.75; 1,10]	7.0 [5,9; 1,10]
Standing difficulty	41.5	7.0 [5,8; 1,10]	7.0 [6,10; 1,10]
Flaky skin**	41.0	5.0 [3,7;1,10]**	4.0 [2,7; 1,10]
Insurance frustration	40.0	8.5 [7,10; 1,10]	9.0 [7,10; 1,10]
Cramping pain	37.8	5.0 [4,8;1,10]	5.0 [3,8; 1,10]
Warmth	35.9	5.0 [3,7.25; 1,10]	4.0 [2,7; 1,10]
Burning pain	35.2	6.0 [4,7;1,10]	6.0 [4,8; 1,10]
Less sexual activity	34.4	7.5 [5,10;1,10]	7.0 [5,9.5; 1,10]
Lack interest in sex*	33.3	8.0 [6,10; 1,10]*	6.5 [5,10; 1,10]
Numbness*	33.0	6.0 [4,7; 1,10]*	5.0 [3,7.75; 1,10]
Pins & needles	29.4	5.0 [3,7; 1,10]	5.0 [3,7; 1,10]
Misunderstood by SO	28.9	7.0 [5,8; 1,10]	7.0 [5,10; 1,10]
Tingling	28.8	5.0 [4,6; 1,10]	5.0 [3,6; 1,10]
Side-to-side difficulty	26.9	6.0 [4,8; 1,10]	7.0 [5,8; 1,10]
Stabbing pain	25.6	6.0 [4,7.5;1,10]	7.0 [5,8; 1,10]
Increased appetite	25.1	7.0 [5,8; 1,10]	8.0 [5,10; 1,10]
Coldness	20.0	5.0 [3,7;1,10]	4.5 [3,7; 1,10]
Partner lack of interest in sex	15.9	7.0 [4,10; 1,10]	7.0 [5,10; 1,10]

* $p < 0.05$; ** $p \leq 0.01$.

meeting friends (20%).²⁶ Unmet sexual needs have also been reported.¹⁶ These studies did not, however, address the intensity of patient symptoms.

It is likely that the higher the intensity of the symptoms a patient experiences the higher the impact on their psycho-

social functioning (such as meeting with friends or attending social events). This potential relationship between the intensity of symptoms and the psychosocial functioning of patients should be explored in future studies. In a systematic review of the quality of life among long-term breast cancer

TABLE 4. DESCRIPTIVES OF SYMPTOM INTENSITY AND DISTRESS BY GROUPS FOR SYMPTOMS WITH HIGHEST PREVALENCE

<i>Symptom*</i>	<i>Symptom prevalence % (Overall)</i>	<i>Symptom Intensity Median [IQR]</i>			<i>Symptom Distress Median [IQR]</i>		
		<i>Cancer</i>	<i>Secondary Non-cancer</i>	<i>Primary</i>	<i>Cancer</i>	<i>Secondary Non-cancer</i>	<i>Primary</i>
Swelling	97.6	6.0 [3,8]	8.0 [5,9]	7.0 [5,9]	6.0 [3,9]	8.0 [4,9]	8.0 [5,9]
Concerns about looks	82.5	9.0 [5,10]	8.0 [6,10]	8.0 [5,10]	8.0 [5,10]	8.0 [5,10]	8.0 [5,10]
Heaviness*	82.0	5.0 [3,7]	7.0 [5,8]	7.0 [4,8]	4.5 [3,7]	7.0 [4,9]	7.0 [5,9]
Tightness	79.7	5.0 [3,7.25]	6.5 [5,8]	7.0 [5,8]	5.5 [2.75,7.25]	7.0 [4,8.25]	7.0 [4,8]
Fatigue	75.9	6.0 [4,7.5]	7.0 [5,8]	7.0 [5,8]	7.0 [2.5,8]	7.0 [4,8]	7.0 [5,8.75]
Less physical activity	70.3	7.0 [3,8]	8.0 [5.75,9.25]	7.0 [5,9]	6.5 [3,10]	8.0 [5,9.5]	8.0 [6,10]
Sadness	68.6	5.0 [3,10]	7.0 [5,9]	6.0 [4,8]	5.5 [2.75,10]	8.0 [5,10]	7.5 [3,8.25]
Lost body confidence	67.3	8.0 [6.25,10]	8.0 [6,10]	7.0 [5,9]	8.0 [5,10]	8.0 [6.25,10]	7.0 [6,10]

Symptoms were reported in >66% of the overall population.

survivors, researchers found that social support (i.e., the number of social contacts and the amount of social involvement with friends and family) was an important predictor of the quality of life of cancer survivors.²⁸ If high levels of symptom intensity correspond with poorer levels of psychosocial functioning, symptom intensity may be an important predictor of the quality of life of patients with lower limb lymphedema.

Similar to symptom intensity, patients reported the highest median levels of distress in the areas of health insurance, body image, and sexuality. For symptoms related to sexuality, participants reported the highest median levels for distress in partner's lack of sexual interest. Sexual dysfunction in patients who underwent radical surgery for gynecological cancers has been reported, with patients with subsequent lower limb lymphedema secondary to cancer treatment experiencing higher unmet sexual needs compared to those without lower limb lymphedema.¹⁶ This study found sexual dysfunction in all groups of patients with lower limb lymphedema and not only those who developed lower limb lymphedema secondary to cancer. Appearance concerns, loss of body confidence, and unmet sexual needs impact the quality of life of patients living with lower limb lymphedema.

Future studies are needed to determine if patients who report high levels of symptom distress experience a lower quality of life compared to those who reported lower levels of symptom distress. Researchers found that breast cancer survivors with better health perceptions and who experienced less stress reported a better quality of life.²⁸ The importance of symptom distress as a potential predictor of the quality of life of patients with lower limb lymphedema should be explored. Qualitative studies are also needed to understand the unmet needs of patients with lower limb lymphedema in the psychosocial domain, with an emphasis on the area of patients' sexuality. With a better understanding of the impact of lymphedema on patient functioning and quality of life, comprehensive care strategies can be employed to address the needs of patients that stretches beyond care in the physical domain. Given the impact of the disease on patients' sexuality, strategies must be employed to also address patients' concerns in this area.

Four categories of individuals with lower limb lymphedema emerged from the study: individuals with primary lymphedema, secondary cancer-related lymphedema, secondary non-cancer-related lymphedema, and lymphedema of unknown cause. Statistically significant differences in symptoms were observed between these groups reporting coldness, lack of confidence in self, and feeling less sexually active.

Specifically, fewer participants in the cancer group reporting these symptoms compared to the primary, secondary non-cancer, and unknown groups. Previous cross-sectional studies, using self-report measures, have compared symptoms in groups of patients with and without lower limb lymphedema.^{16,27} In these studies, those with lymphedema experienced a lower quality of life and a higher odds ratio of experiencing psychological, physical, daily living, and sexual unmet needs. These studies, however, compared patients with and without lymphedema following treatment for gynecological malignancies.

The current study adds to the body of literature by comparing symptoms between patients with primary or secondary (cancer- and non-cancer-related) lower limb lymphedema and those with

lower limb lymphedema of unknown cause, finding that patients in the cancer-related lower limb lymphedema group experience fewer symptoms in three specific areas: coldness, lack of confidence in self, and feeling less sexually active.

In one of the few comparisons of the quality of life self-assessment scores between patients with primary versus secondary lower limb lymphedema, patients with secondary lower limb lymphedema scored lower in the areas of vitality and physical functioning.²⁹ Out of a maximum score of 100, patients with primary lower limb lymphedema scores ranged from 70.0–83.1 versus 63.3–80.6 for secondary lower limb lymphedema. This current study extends the work by Huggenberger and colleagues by finding differences in symptoms reported by those with cancer-related vs. non-cancer-related lower limb lymphedema.²⁹ Future studies comparing lower limb lymphedema in patients should further differentiate the secondary lower limb lymphedema group as cancer-related versus non-cancer-related groups to enhance our understanding of patients and their experiences with lower limb lymphedema.

Statistically significant differences were observed between groups in terms of intensity and distress related to various symptoms. Compared to other groups, patients in the cancer group experienced a lower intensity of symptoms for numbness and achiness in their legs and less flakiness of the skin. Although high distress symptoms were reported for insurance frustration, lack of confidence in insurance, partner lack of interest in sex, increased appetite, appearance concerns and loss of body confidence, no statistically significant differences were observed between the groups.

Lower health-related quality of life has been reported in breast cancer survivors with lymphedema compared to those without a diagnosis of lymphedema.^{11,30} Similar research in patients with lower limb lymphedema is limited.²⁷ This study addressed that limitation by evaluating individuals with lower limb lymphedema and the prevalence, intensity, and distress of symptoms. As demonstrated by Sawan and colleagues,³¹ interventions targeting the physical symptoms of lower limb lymphedema may have a spill-over effect in the areas of psychosocial well-being. However, because of the level of intensity and distress in symptoms experienced by patients, treatment of patients with lower limb lymphedema should focus on interventions to address both the physical and psychosocial well-being of patients and seek ways to address insurance frustrations and concerns and problems related to patients' sexuality.

Limitations of the study need to be considered when interpreting the results. Due to the cross-sectional design of the study, causality cannot be inferred. Because of the recruitment strategies used, not all individuals with lower limb lymphedema may have been made aware of the study. Therefore, the data may not be representative of the population of patients with lower limb lymphedema. Also, in this study, data that were self-reported by patients were used, increasing the risk for response bias. However, steps were taken to reduce this risk by ensuring participants of the confidentiality and anonymity of the data and subsequent reporting.

Conclusions

A variety of physical and psychosocial symptoms are highly prevalent in patients with cancer and non-cancer related lower limb lymphedema. Compared to physical symptoms, the

intensity of psychosocial symptoms are, however, more severe. Patients struggle with appearance concerns, body confidence, and sexuality, which impact their quality of life and social functioning. When comparing groups and the prevalence and intensity of symptoms, for some symptoms, patients with cancer-related lower limb lymphedema experienced fewer and less intense physical and psychosocial symptoms. Distress related to physical and psychosocial symptoms were similar across groups.

These findings have important implications for clinical practice. An evaluation of the physical and psychosocial health of patients with lower limb lymphedema, regardless of type of lymphatic disruption, must be a standard care practice. When necessary, interventions that address both physical and psychosocial symptoms should be included in the patient's plan of care. Therapeutic goals should include interventions that will facilitate improvements in patients' social functioning and their quality of life. Patients should be evaluated, in particular, for symptoms of fatigue and pain and concerns about their insurance, appearance and body confidence, as well as their sexuality.

Future research should elucidate further the impact of lower-limb lymphedema on the quality of life and social functioning of patients. Exploratory research is needed to examine why cancer patients experience less symptoms and less intensity in some symptom areas compared to non-cancer, primary, and unknown groups.

Acknowledgments

Grant support for the utilization of REDCap™ was provided. (UL1 TR000445 from NCATS/NIH). This work was funded by the Vanderbilt School of Nursing Martha Rivers Ingram Chair of Nursing.

Author Disclosure Statement

No competing financial interests exist.

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