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SYMPTOM BURDEN AND INFECTION OCCURRENCE AMONG INDIVIDUALS WITH EXTREMITY LYMPHEDEMA

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ABSTRACT

Currently, there is a lack of data related to differences in symptoms and infection across different types and anatomical sites of lymphedema. The objective of this study was to examine differences in symptoms and infection status among individuals with lymphedema of the upper or lower extremities. The National Lymphedema Network initiated an online survey of self-report lymphedema data from March 2006 through January 2010. Descriptive statistics, Mann-Whitney tests, and Chi-square tests were used to analyze data. 723 individuals with upper extremity lymphedema and 1114 individuals with lower extremity lymphedema completed the survey. Individuals with extremity lymphedema experienced high symptom burden and infectious complications. Compared with individuals with upper extremity lymphedema, individuals with lower extremity lymphedema experienced more frequent and more severe symptoms (p<.001), infection episodes (p<.001), and infection-related hospitalizations (p<.001). No statistically significant differences of symptom burden and infection status were identified between individuals with lower extremity primary and secondary lymphedema.

Individuals with extremity lymphedema experience substantial symptom burden and infectious complications; however, those with lower extremity lymphedema have more severe symptoms and more infections than those with upper extremity lymphedema.

Keywords: symptom, infection, extremity lymphedema, primary lymphedema, secondary lymphedema

Lymphedema is a life-long, but manageable, condition that can have a significant impact on individuals' daily functioning, work productivity, and quality of life (QOL) (1), and can also create financial burden for individuals and their families (2-5). Lymphedema can be classified as either primary or secondary; may be mild, moderate, or severe; and may be transient, episodic, or chronic in nature.

Although the etiology is not yet fully understood (6-7), primary lymphedema is related to an inherent defect with the lymphatic system that is often associated with mutation in gene(s) involved in the process of

lymphangiogenesis (8-12). Primary lymphedema may be present at birth (i.e., congenital lymphedema) or may become evident later in life. For example, lymphedema praecox generally occurs prior to the age of 35 years (e.g., in girls during puberty), whereas late-onset lymphedema tardum may occur in individuals more than 35 years of age (5-6). The estimated incidence of primary lymphedema reported in the literature is about 1 in 6,000 births, which can be extrapolated to around 1 million carriers of the lymphedema-associated gene(s) in the United States (13).

Secondary, or acquired, lymphedema is the most common type of lymphedema in developed countries (2,5). It is estimated that between 2 and 3 million individuals in the United States experience secondary lymphedema. Although secondary lymphedema largely results from cancer and its treatment, it can also result from other trauma or overuse of the lymphatic system (e.g., traumatic injuries, burns, large or circumferential wounds, infection, pregnancy, venous disease, and obesity) (14).

It is difficult to determine the overall population burden of primary and secondary lymphedema as it is often either under- or mis-diagnosed (5). Currently, lymphedema is not considered a curable condition. It is most frequently seen as a chronic condition that requires individuals' long-term involvement in treatment and self-care management. Sufficient high-level evidence based on rigorous research is not available to conclusively support recommendations for treatment and self-care strategies in individuals with primary and/or secondary lymphedema. Recent studies reported that lymphedema remains poorly understood among healthcare professionals and is frequently under-diagnosed and under-treated (15-16). Qualitative studies have vividly described significant distress and symptom burden among individuals with lymphedema (15-17). Therefore, to increase healthcare professionals' awareness and provide them with evidence-based data for addressing the critical needs and issues related to lymphedema management, it is imperative for investigators to elicit and synthesize accurate information related to lymphedema from patients' perspectives. The current study was designed to address this need. Specifically, survey data collected by the National Lymphedema Network (NLN) was used to examine patients' perceptions about symptom experience, infection status, and infection complications.

Since 2006, the NLN has collected data using a web-based survey to identify key information related to primary and secondary lymphedema and explore the overall patient burden associated with lymphedema. Approximately 20% of the surveys were received via postal mail. The survey consisted of two sections. Part 1 focused on collecting information related to lymphedema occurrence, symptom burden, access to treatment, and self-care information. Part 2 asked respondents about where and how they obtained education and particular information about lymphedema management. The findings reported here exclusively involved the analysis of data collected in Part 1 of the survey, with a focus on data from a subset of respondents (70%) with extremity lymphedema. The aims of the study were to determine whether or not there were differences in self-reported symptom burden and infection occurrence among individuals with upper or lower extremity and primary or secondary lymphedema of upper or lower extremities. It was hypothesized that symptoms and infection status differed between individuals with upper or lower extremity lymphedema (Hypothesis 1) and between those with primary or secondary lymphedema (Hypothesis 2). In addition, it was postulated that individuals with a high symptom burden were also more likely to report repeated episodes of infection, regardless of the etiology or lymphedema involvement of upper or lower extremities (Hypothesis 3).

METHODS

Survey Development

The NLN web-based survey (Part 1) was developed by the NLN Research Subcommittee in 2006, using an iterative process that included: a) item generation; b) review and revision by clinical experts; and c) final review and approval by the NLN Research Subcommittee. The final questionnaire consisted of 16 components that focused on the collection of information related to respondents: demographics, type of lymphedema, characteristics of primary lymphedema, affected area(s), surgical treatment, other causes of lymphedema, infection status, associated symptoms, self-care regimens, prior history of complete decongestive therapy (CDT) or manual lymph drainage (MLD), alternative treatments explored, quality of life (QOL), insurance status and coverage policies, and open-ended questions aimed at eliciting responses related to their perception of the most critical issues in their personal experiences with lymphedema.

Survey Administration

The survey was posted on the NLN's website (www.lymphnet.org) beginning in 2006. Solicitation for participation in the survey was initiated using the NLN Lymph Link, websites, NLN members and support groups' mails, lectures, advertisements, and through attending national and international conferences. The survey was accessible to individuals in the United States and worldwide. Completion of the survey served as the respondents' consent to participate in this web-based survey study. The data reported in this article were collected from March 2006 to January 2010. The study was approved by the University of Missouri Health Sciences Institutional Review Board (IRB) and the secondary data analysis was approved by the IRB at Vanderbilt University.

Data Downloading and Verification

Raw data were downloaded using a Microsoft Excel spreadsheet. The Human-in-the-loop (HITL) method (18) steps were used to verify and clean data by screening for duplicate respondents and invalid cases, which were defined as surveys with missing data on key study variables.

Statistical Analysis

Data were analyzed using the statistical software package SPSS version 19.0. Descriptive statistics were used to summarize the characteristics of the cohort. Medians as well as 25th and 75th interquartile (IQR) ranges were used to report continuous variables. Frequency distributions summarized nominal characteristics. Comparisons between distress levels of symptoms among different groups were conducted using Mann-Whitney tests for the continuous variables. Respective comparisons for nominal characteristics were conducted using chi-square tests of independence. Spearman's correlation was used to examine the associations of symptom occurrences with infection episodes. A maximum alpha of 0.01 was used for evaluating statistical significance.

RESULTS

Sample

From March 2006 through January 2010, a total of 2,968 surveys were completed. Following the deletion of duplicate surveys (n=220) and those with invalid responses (n=14), data from a final cohort of 2734 respondents were available for analysis. The most frequently identified anatomic distribution for lymphedema in the cohort was extremity lymphedema (n=1929, 71%). Thus, the findings in this study are based exclusively on respondents with reported primary or secondary extremity lymphedema. Because of an insufficient number of

individuals with reported upper extremity primary lymphedema (n=12), we were unable to make valid comparisons between individuals with upper extremity primary and secondary lymphedema.

Distribution of Lymphedema

With respect to the reported type of lymphedema, 66% of the respondents reported having secondary lymphedema, while 30% reported having primary lymphedema, and 4% did not indicate type of lymphedema. Regarding the anatomical sites of lymphedema, 71% (n=1929) of the respondents reported extremity lymphedema only, 22% reported combined extremity(s) and other anatomic sites of lymphedema (e.g., breast and trunk), 3% reported having non-extremity lymphedema, and 4% did not indicate site of lymphedema. The distribution of the respondents with extremity lymphedema (n=1929) was categorized based on anatomic location and etiology: (1) 36% had upper extremity secondary lymphedema; (2) 31% had lower extremity primary lymphedema; (3) 28% had lower extremity secondary lymphedema; (4) 2% had both upper and lower extremities primary lymphedema; (5) 2% had both upper and lower extremities secondary lymphedema; and (6) 1% had upper extremity primary lymphedema.

Hypothesis 1: Comparison of Upper versus Lower Extremity Lymphedema

Sample characteristics

Table 1 summarizes the characteristics of individuals with upper or lower extremity lymphedema. Statistically significant differences were noted for gender, annual household income, insurance coverage, cancer-related surgery (yes/no), type of surgery, and CDT/MLD treatment (yes/no) among individuals with upper or lower extremity lymphedema. Male participants were less likely to have upper extremity lymphedema. Compared to individuals with upper extremity lymphedema, individuals with lower extremity lymphedema were more likely to report lower annual household income, poorer insurance coverage, less cancer-related surgery, and less likely to receive CDT/MLD treatment Approximately 24% of responding participants engaged in both CDT and alternative treatments, 36% were engaged in neither, and the remainder (40%) were doing CDT/MLD or some alternative treatment.

Symptoms profiles

Regardless of the anatomic sites of lymphedema, a high percentage of individuals with extremity lymphedema reported symptoms (*Table 2*). Symptoms experienced most frequently among individuals with upper extremity lymphedema were swelling (96.8%), heaviness (76.2%), current pain (67.3%), stiffness (65.8%), numbness (63.9%), and poor range of motion (48.0%). Symptoms experienced most frequently among individuals with lower extremity lymphedema were swelling (98.7%), heaviness (87.1%), stiffness (76.3%), current pain (69.8%), poor range of motion (65.8%), and numbness (59.2%). Moreover, individuals with lower extremity lymphedema were more likely to experience frequent symptoms (i.e., swelling, heaviness, stiffness, and poor range of motion) and more distressing symptoms (i.e., swelling, heaviness, stiffness, current pain, numbness, and poor range of motion) than individuals with upper extremity lymphedema ($p<.001$). Thus, our hypothesis that symptoms among individuals with upper or lower extremity lymphedema differed was supported.

Infection status

A high percentage of individuals with extremity lymphedema reported infections regardless of the anatomical sites. Compared to individuals with upper extremity

TABLE 1
Characteristics of Respondent Cohort Stratified by Upper (n=723) versus Lower (n=1114) Extremity Lymphedema

Characteristic	Upper Extremity (n=723) Number (%)	Lower Extremity (n=1114) Number (%)	p-value
Gender*			<.001
Female	674 (95.6)	893 (81.9)	
Male	31 (4.4)	198 (18.1)	
(total responses)	705 (100.0)	1091(100.0)	
Ethnicity*			.048
Caucasian	565 (81.5)	855 (79.6)	
African-American	41 (5.9)	102 (9.5)	
Hispanic	17 (2.5)	24 (2.2)	
Other	70 (10.1)	93 (8.7)	
(total responses)	693 (100.0)	1074 (100.0)	
Country			.213
USA	687 (95.0)	1036 (93.0)	
Canada	11 (1.5)	23 (2.1)	
Other	25 (3.5)	55 (4.9)	
(total responses)	723 (100.0)	1114 (100.0)	
Annual household income*			.001
<$ 30,000	139 (23.6)	304 (32.1)	
$30,000-$44,999	110 (18.6)	173 (18.3)	
>$45,000	341 (57.8)	469 (49.6)	
(total responses)	590 (100.0)	946 (100.0)	
Insurance coverage*			<.001
Yes	490 (70.4)	596 (54.5)	
No	50 (7.2)	131 (12.0)	
Don't know	156 (22.4)	367 (33.5)	
(total responses)	696 (100.0)	1094 (100.0)	
Type of insurance*			.063
Government	90 (18.4)	139 (23.3)	
Private	298 (60.8)	323 (54.2)	
Other	102 (20.8)	134 (22.5)	
(total responses)	490 (100.0)	596 (100.0)	
Cancer-Related Surgery			<.001
Yes	683 (94.5)	275 (24.7)	
No	40 (5.5)	839 (75.3)	
(total responses)	723 (100.0)	1114 (100.0)	
Type/Site of Surgery*			<.001
Breast	607 (93.0)	35 (14.4)	
Gynecological	1 (0.2)	117 (48.0)	
Prostate	0 (0.0)	6 (2.4)	
Melanoma	23 (3.5)	34 (13.9)	
Other	22 (3.4)	52 (21.3)	
(total responses)	653 (100.0)	243 (100.0)	
CDT/MLD*			<.001
Yes	338 (53.6)	420 (39.8)	
No	258 (40.9)	577 (54.7)	
Don't know	35 (5.5)	57 (5.4)	
(total responses)	631 (100.0)	1054 (100.0)	
Use of Alternative treatment*			.029
Yes	225 (38.3)	439 (43.9)	
No	362 (61.7)	560 (56.1)	
(total responses)	587 (100.0)	999 (100.0)	

*Only valid cases

TABLE 2
Reported Symptoms among Respondents with Upper and Lower Extremity Lymphedema

	Reported Symptoms			If Present, Severity of Distress Related to Symptoms		
Symptom	Upper Extremity	Lower Extremity	p-value	Upper Extremity	Lower Extremity	p-value
	Number (%)	Number (%)		Median (IQR)	Median (IQR)	
Swelling	614 of 634 (96.8)	1049 of 1063 (98.7)	.009	2 (1,2)	2 (2,3)	<.001
Heaviness	480 of 630 (76.2)	910 of 1045 (87.1)	<.001	3 (2,4)	4 (3,4)	<.001
Stiffness	416 of 632 (65.8)	794 of 1041 (76.3)	<.001	2 (1,3)	3 (2,4)	<.001
Current pain	429 of 637 (67.3)	740 of 1060 (69.8)	.288	2 (1,3)	3 (2,4)	<.001
Numbness	404 of 632 (63.9)	619 of 1046 (59.2)	.053	2 (1,3)	3 (2,3)	<.001
Poor range of motion	304 of 633 (48.0)	692 of 1051 (65.8)	<.001	2 (2,3)	3 (2,4)	<.001

Note: Severity of Distress Related to Symptoms: Little (1) to Extreme (5)

lymphedema, individuals with lower extremity lymphedema experienced more frequent infection episodes (41.7% vs. 24.6%, p<.001) and infection-related hospitalizations (24.8% vs. 9.1%, p< .001). Thus, our hypothesis that infection status would differ between individuals with upper or lower extremity lymphedema was supported.

Hypothesis 2: Comparison of Primary versus Secondary Lower Extremity Lymphedema

Sample characteristics

Table 3 summarizes the characteristics of individuals with lower extremity primary or secondary lymphedema. Statistically significant differences were found between the groups with respect to ethnicity, insurance coverage, and cancer-related surgery. Compared to individuals with lower extremity primary lymphedema, individuals with lower extremity secondary lymphedema were more likely to be Caucasian with better insurance coverage and to have undergone cancer-related surgery.

Symptoms profiles

Regardless of etiology of lymphedema, a high percentage of individuals with lower extremity lymphedema reported symptoms (*Table 4*). Similar symptom burdens were reported among individuals with lower extremity primary and secondary lymphedema. Therefore we did not find support for our hypothesized differences (*Table 4*).

Infection status

A high percentage of individuals with lower extremity primary and secondary lymphedema reported infections. No statistically significant differences were noted with respect to infection status (42.4% vs.

TABLE 3
Demographic and Treatment Characteristics among Respondents with Lower Extremity Primary and Secondary Lymphedema

Characteristic	Primary (n=571) Number (%)	Secondary (n=526) Number (%)	p-value
Gender*			.087
Female	473 (83.9)	408 (79.8)	
Male	91 (16.1)	103 (20.2)	
(total responses)	564 (100.0)	511 (100.0)	
Ethnicity*			<.001
Caucasian	414 (74.5)	430 (85.3)	
African-American	81 (14.6)	21 (4.2)	
Hispanic	13 (2.3)	10 (2.0)	
Other	48 (8.6)	43 (8.5)	
(total responses)	556 (100.0)	504 (100.0)	
Country			.321
USA	524 (91.8)	495 (94.1)	
Canada	14 (2.5)	9 (1.7)	
Other	33 (5.8)	22 (4.2)	
(total responses)	571 (100.0)	526 (100.0)	
Annual household income*			.822
<$ 30,000	160 (32.4)	138 (31.3)	
$30,000-$44,999	92 (18.6)	78 (17.7)	
>$45,000	242 (49.0)	225 (51.0)	
(total responses)	494 (100.0)	441 (100.0)	
Insurance coverage*			.004
Yes	283 (50.0)	307 (60.1)	
No	73 (12.9)	57 (11.2)	
Don't know	210 (37.1)	147 (28.8)	
(total responses)	566 (100.0)	511 (100.0)	
Type of insurance*			.161
Government	56 (19.8)	81 (26.4)	
Private	162 (57.2)	159 (51.8)	
Other	65 (23.0)	67 (21.8)	
(total responses)	283 (100.0)	307 (100.0)	
Cancer-related Surgery			<.001
Yes	21 (3.7)	250 (47.5)	
No	550 (96.3)	276 (52.5)	
(total responses)	571 (100.0)	526 (100.0)	
Type/Site of Surgery*			.428
Breast	3 (18.8)	30 (13.4)	
Gynecological	6 (37.5)	110 (49.1)	
Prostate	0 (0.0)	6 (2.7)	
Melanoma	1 (6.3)	32 (14.3)	
Other	6 (37.5)	46 (20.5)	
(total responses)	16 (100.0)	224 (100.0)	
CDT/MLD*			.200
Yes	210 (38.3)	207 (42.2)	
No	313 (57.0)	254 (51.7)	
Don't know	26 (4.7)	30 (6.1)	
(total responses)	549 (100.0)	491 (100.0)	
Use of Alternative treatment*			.627
Yes	238 (45.0)	199 (43.4)	
No	291 (55.0)	259 (56.6)	
(total responses)	529 (100.0)	458 (100.0)	

* Only valid cases. CDT/MLD = complete decongestive therapy/manual lymph drainage

TABLE 4
Comparisons of Symptoms between Lower Extremity Primary Lymphedema (n=571) and Lower Extremity Secondary Lymphedema (n=526)

	Reported Symptoms			If Present, Severity of Distress Related to Symptoms		
Symptom	Primary	Secondary	p-value	Primary	Secondary	p-value
	Number (%)	Number (%)		Median (IQR)	Median (IQR)	
Swelling	545 of 553 (98.6)	488 of 494 (98.8)	.744	2 (2,3)	2 (2,3)	.414
Heaviness	478 of 544 (87.9)	418 of 486 (86.0)	.376	3 (1,4)	3 (1,4)	.869
Stiffness	412 of 543 (75.9)	372 of 484 (76.9)	.711	2 (0,3)	3 (0,4)	.111
Pain	378 of 550 (68.7)	348 of 495 (70.3)	.581	2 (0,3)	2 (0,3)	.746
Numbness	311 of 544 (57.2)	296 of 487 (60.8)	.239	1 (0,3)	1 (0,3)	.124
Poor range of motion	345 of 547 (63.1)	338 of 490 (69.0)	.045	1 (0,3)	2 (0,3)	.024

Note: Severity of Distress Related to Symptoms: Little (1) to Extreme (5)

41.4%, p>.05) and infection-related hospitalizations (26.4% vs. 23.2%, p>.05) among individuals with lower extremity primary or secondary lymphedema. Therefore, as with symptoms, we did not find support for our hypothesized differences.

Hypothesis 3: Association between Symptoms and Infection Status

As postulated, individuals with more frequent self-reported lymphedema symptoms also reported more episodes of infection (p<.001). However, there were no statistically significant differences between individuals with 1) upper and lower extremity lymphedema; or 2) lower extremity primary and secondary lymphedema. Thus, our hypothesis that individuals with a high symptom burden were also more likely to report repeated episodes of infection, regardless of the etiology or lymphedema involvement of upper or lower extremities was supported.

DISCUSSION

In this web-based survey developed by the NLN, 95% of respondents were from the United States. There was a significant distribution of reported lymphedema in terms of etiology and anatomical sites of lymphedema; 66% of respondents had secondary lymphedema and 30% had primary lymphedema. This finding is consistent with the estimates from the literature that secondary lymphedema is more common, with an estimated 2 to 3 million affected persons compared to 1 to 2 million individuals with primary lymphedema in the United States (19).

It is also consistent with published reports that 70% of respondents reported lymphedema of the extremities only (2,5). A much greater percentage of respondents with upper extremity lymphedema had secondary compared to primary lymphedema (36% versus 1%). This is consistent with studies reporting upper extremity lymphe-

dema in developed countries is largely related to cancer and risk factors related to its treatment (6,20). Thirty-one percent of respondents reported lower extremity primary lymphedema in comparison to 28% of those reporting lower extremity secondary lymphedema. This finding is also consistent with published estimates about lower extremity lymphedema (21).

Clearly, substantial symptom burden was reported by individuals with extremity lymphedema regardless of the affected site, with greatest symptom burden in those with lower extremity lymphedema. Further, this study indicated that symptom burden in all cases of extremity lymphedema is substantially higher than previously reported. An earlier study of women with upper extremity lymphedema (4) as compared with this study found the following symptoms respectively: swelling (63% versus 96.8 %), heaviness (60% versus 76.2%), and numbness (38% versus 63.9%). Similarly, a study of those with lower extremity lymphedema (22) compared with this study found the following symptom respectively: heaviness (46% versus 87.1%), pain (41% versus 69.8%), and swelling (not indicated versus 98.7%). It is possible self-selection by survey participants yielded a sample reporting higher symptoms burden than other published studies.

Another important finding from this survey analysis was that approximately 25% of individuals with upper extremity lymphedema and 40% with lower extremity lymphedema reported episodes of infection. One quarter of individuals with lower extremity lymphedema were hospitalized for the treatment of a lymphedema-related infection. In addition, individuals with more symptoms were more likely to have episodes of infection, regardless of the anatomical locations and type of extremity lymphedema. While a common precursor to the development or exacerbation of lymphedema is infection (23,24), more severe symptoms could also indicate poor lymphedema management, which may exacerbate lymphatic system burden and predispose affected areas to bacterial overgrowth (6,25).

It is important to note that individuals with lower extremity lymphedema experienced more frequent or more distressing symptoms and infection episodes, as compared to individuals with upper extremity lymphedema. While no published comparison studies are available for review, this generates important questions, such as the following: Why are there differences in symptoms and infection status between these two groups? Are these differences related to underlying lymphedema pathophysiology, treatment, self-care, or any other contributing factors? Several possible explanations may be attributed to this finding. First, certain demographic and treatment characteristics differed between these two groups. Compared with individuals with upper extremity lymphedema, individuals with lower extremity lymphedema reported significantly lower annual household income and poorer insurance coverage; a higher percentage of individuals had not received CDT/MLD treatment. Those demographic and treatment-related factors may account for the increased rate in symptom burden and infection episodes among individuals with lower extremity lymphedema. Second, the increased hydrostatic pressure of the lower extremities may have a direct impact on lymphatic drainage, such that individuals with lower extremity lymphedema may be more likely to have poor lymphatic drainage compensation capacity and, therefore, may be more vulnerable to bacterial overgrowth (25-26). Third, individuals with lower extremity lymphedema may experience more self-care difficulties and have to maintain more static positions than individuals with upper extremity lymphedema. These findings indicate that: 1) more studies are needed to further examine and/or replicate these results; and 2) studies are warranted to explore the risk factors contributing to the symptom burden in individuals with extremity lymphedema.

Several strengths are associated with this cross-sectional survey study. Based on the large number of respondents using a survey that included a detailed symptom assessment, we were able to identify substantial symptom burden and infection complications, which provide insight related to the clinical significance of symptom management and reduction of infections to improve QOL among individuals with lymphedema. Further, the study compares the differences in symptoms and infection status among individuals with upper versus lower extremity, and primary versus secondary lower extremity. These comparisons have not been reported previously, and additional studies are needed to verify these differences and explore potential underlying factors related to these discrepancies. Finally, these data demonstrate an association between symptom burden and infectious episodes, upholding the importance of symptom surveillance and management in the individuals with lymphedema. Additional studies are warranted to further examine the associations between symptoms and infection status among individuals with lymphedema.

A number of limitations should be acknowledged when interpreting these results. First, the data collected were cross-sectional rather than longitudinal and the participants were self-selected for participation. Causal relationships cannot be examined in a cross-sectional study. The survey queried about only the six symptoms reported; it is possible other symptoms were overlooked. Also, the study used self-reported data without access to medical history, which may contain potential selective memory bias.

Despite these limitations, the study findings highlight a number of important issues related to lymphedema management. First, symptom management remains an under-addressed problem for reasons that are yet unclear. Given that there is currently no cure for lymphedema, it is critically important that individuals with lymphedema, as well as family members and healthcare providers, are educated and become aware that lymphedema symptoms can be managed. Supportive interventions are required for those with lymphedema to assist with the on-going day-to-day management. Second, education in prevention, signs and symptoms, and early treatment of infections need to be emphasized and implemented by healthcare professionals assisting with lymphedema care. To identify patients in the early phases of lymphedema, healthcare professionals need to be educated and conduct routine screening for early lymphedema symptoms and provide referrals to lymphedema specialists for individualized lymphedema management plans. Third, individuals with lower extremity lymphedema are at particularly high risk for developing lymphedema-associated symptoms and infections. Our current focus is to update the present NLN web-based survey for individuals with lymphedema to include additional symptoms and management strategies with reported symptoms, and to explore factors potentially contributing to symptom burden and infection complications.

CONCLUSION

Individuals with extremity lymphedema experience substantial symptom burden and infection complications. Lower extremity lymphedema is associated with more distressing symptoms and more infections than upper extremity lymphedema regardless of etiology. Factors contributing to symptom burden and infection complications and supportive interventions for extremity lymphedema need to be further investigated. Healthcare professionals and clinical investigators need to be educated in lymphedema management and risk reduction practices and take an active role in designing and implementing effective approaches and evidence-based interventions for the best management of lymphedema.

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