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A comparison of the quality of life in patients with primary and secondary lower-limb lymphedema: A mixed-methods study

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Abstract

Patients with lower-limb lymphedema experience symptoms that may differ in intensity and distress. This mixed-methods study compares symptom intensity and distress and the impact of lymphedema on patients' quality of life by primary and secondary (cancer and non-cancer) lymphedema groups. Individuals completed an online questionnaire (i.e., demographic form, Lymphedema Symptom Intensity and Distress Survey-Leg, and an open-ended question). Analyses included descriptive and inferential statistics (quantitative data) and content analysis (qualitative data). Participants differed statistically significantly by gender, employment status, and lymphedema location. Groups differed significantly in lack of self-confidence ($\chi^2_{(df=2)}$ =9.19; p=.010). Cancer patients reported higher intensity and distress scores for some symptoms, but these differences were not statistically significant. Patients reported lacking psychosocial well-being and resources and experiencing physical and functional impairments and treatment and care challenges. Patients with lower-limb lymphedema experience psychosocial impairments and problems with quality of and access to care.

Keywords

Lymphedema; lymphatic disease; primary congenital lymphedemas; quality of healthcare; cancer

Lymphedema is a chronic, incurable, and often debilitating condition that develops due to disruption in the lymphatic circulation and subsequent impairment in lymphatic drainage. (Finnane, Hayes, Obermair, & Janda, 2011; Jensen, Simonsen, Karlsmark, & Bulow, 2010; Murdaca et al., 2012). If untreated, lymphedema may progress to chronic inflammation and infection that can lead to further damage of lymph vessels with subsequent skin changes, disfigurement and functional impairment of the affected limbs (Chachaj et al., 2010; Jensen et al., 2010; Noble-Jones, Fitzpatrick, Sneddon, Hendry, & Leung, 2014).

PRIMARY AND SECONDARY LYMPHEDEMA

Lymphedema is either primary or secondary in nature (McWayne & Heiney, 2005; Murdaca et al., 2012; Noble-Jones et al., 2014). Primary lymphedema is a clinical manifestation of a

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defect in the lymph vessels or nodes and, based on the age of symptom onset and clinical manifestation(Kerchner, Fleischer, & Yosipovitch, 2008; Murdaca et al., 2012). Secondary lymphedema is primarily due to damage to the lymphatic system caused by malignancy, surgery, trauma, infection or radiation therapy, leading to obstruction or disruption of the system (Jensen et al., 2010; Murdaca et al., 2012). It is most often a consequence of malignancy or malignancy-associated treatments and a significant cancer survivorship problem (Ahmed, Prizment, Lazovich, Schmitz, & Folsom, 2008; Akita et al., 2013; V. L. Beesley et al., 2015; Deng, Ridner, Murphy, & Dietrich, 2012; Fu, 2014; Kim et al., 2015; Novackova et al., 2012).

Patients with primary and secondary lymphedema experience a high symptom burden with physical and psychosocial sequela of the disease (V. Beesley, Janda, Eakin, Obermair, & Battistutta, 2007; Cromwell et al., 2015; Fu, 2014). Physical symptoms include swelling, tightness, pain/tenderness, heaviness, and impaired mobility of the affected limb (Kerchner et al., 2008; Kim et al., 2015). The psychosocial impact of lymphedema is evident with many patients struggling with interpersonal relationships, self-image and self-esteem, loss of confidence, psychological distress, lower quality of life, and issues with time management and sleep disturbances (Dunberger et al., 2013; Fu & Kang, 2013; Hulett, Armer, Stewart, & Wanchai, 2015). Studies of patients with primary and secondary *lower-limb* lymphedema similarly indicate the disease’s psychosocial impact with poor physical function and a lower quality of life (Brown et al., 2014; Deng et al., 2015; Finnane et al., 2011; Fu & Kang, 2013; Huggenberger et al., 2015; Novackova et al., 2012; Symvoulakis, Anyfantakis, & Lionis, 2010).

Differences that may exist in the psychosocial well-being of patients with primary versus secondary, cancer and non-cancer related *lower-limb* lymphedema are relatively unexplored. Studies have compared patients with upper- and lower-extremity lymphedema (Deng et al., 2013; Noh et al., 2015), primary and secondary lymphedema (Deng et al., 2013; Huggenberger et al., 2015; Lam, Wallace, Burbidge, Franks, & Moffatt, 2006), primary and secondary cancer-related lymphedema (Maxeiner, Saga, Downer, & Arthur, 2009) and patient with lymphedema versus patients without lymphedema (Brown, Chu, Cheville, & Schmitz, 2013), with multiple studies focusing on breast-cancer survivors (Chachaj et al., 2010; Speck et al., 2010). Due to a lack of studies, it is unclear if patients with primary and secondary cancer-related vs. non-cancer related lower-limb lymphedema are impacted in similar ways by the disease. Therefore, as part of an ongoing series of instrument development studies, data were collected regarding symptoms related to lower-limb lymphedema. This manuscript leverage data from the aforementioned study to describe and compare the impact of lower-limb lymphedema on the quality of life of patients with the disease by lymphedema type (i.e., primary, secondary cancer-related, and secondary non-cancer-related). An understanding of the quality of life challenges patients experience will guide healthcare providers in the selection of patient screening tools to identify problems and treatment decisions that are tailored to the patient’s physical and psychosocial needs.

PURPOSE

The purpose of this study was to describe and compare the impact of the symptoms of lower-limb lymphedema and the associated symptom intensity and distress on the quality of life of patients by lymphedema type. Quality of life was defined as an individual's subjective well-being and satisfaction with their life related to the physical, emotional, and social functioning (Bowling & Iliffe, 2011). The specific research questions were: "Do symptom prevalence and symptom intensity and distress differ in patients with lower-limb lymphedema by lymphedema type? "and "What symptoms or problems do patients with lower-limb lymphedema perceive as affecting their quality of life?" A drilldown comparing those with secondary cancer-related lower-limb lymphedema and those with non-cancer-related lower-limb lymphedema was also conducted. Institutional Review Board (IRB) approval for exempt status was received from Vanderbilt University.

METHODS

Design

This study employed a mixed-methods design using an on-line accessible survey methodology.

Participants

Several recruitment strategies were used to recruit participants: study flyers that were posted at the National Lymphedema Network and the Lymphatic Education and Research Network; a posting on the website www.lympdemablog.com; and, a mass email was sent to Vanderbilt University faculty and staff. Study staff screened all individuals who were interested in participating in the study and who contacted the study office for eligibility. Eligibility criteria included individuals who were 18 years of age or older, could read and speak English and, had been told by a healthcare team member that they had lower limb lymphedema. Study staff provided all potential participants with information about the study and any potential risks and benefits associated with participation. Potential participants were assured of the confidentiality of their responses on the study website and also verbally by study staff who screened potential participants. Participants who met the eligibility criteria were enrolled in the study. Recruitment took place from February 8 to September 26, 2012.

Data Collection

Volunteers who were willing to participate in the study were provided with a unique code to access and complete the confidential, web-based survey by logging into the Research Electronic Data Capture (REDCap™) program website. The survey consisted of three data collection tools namely a demographic form, the Lymphdema Symptom Intensity and Distress Survey-Leg (LSIDS-L), and one open-ended qualitative question.

Demographic form—The demographic form consisted of questions related to 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). The survey started by asking participants whether symptoms was present (“Yes” or “No”) and, if “Yes”, participants were asked to rate the intensity and distress associated with the symptom on two separate 10-point scales (1=slight to 10=severe). Intensity was defined as the actual severity of the symptom itself while distress was defined as the physical or emotional response to a symptom. Participants who indicated “yes” to swelling in their abdomen, back, or groin completed an additional section of questions (not reported here). Because of the sensitive nature of some questions, participants had the option of answering “prefer not to answer” for questions related to feeling less sexually attractive, lacking interest in sex or partner lacking interest in sex. The overall number of items to which a participant responded ranged from a minimum of 46 to a maximum of 177. For the purpose of this manuscript, only questions related to psychosocial symptoms and insurance-related questions (i.e., insurance frustration and lack of confidence in insurance), (i.e., LSIDS-Legs survey items numbers 19 – 36) and the related intensity and distress questions were included.

Open ended question—Participants were asked one open-ended question, “Please list any other symptoms or problems related to your legs swelling that we did not ask”. The purpose of this question was to gather additional information from participants on any symptoms that were not covered within the 36 structured items. Participants could elect not to answer this question and still be in the study.

Data Analyses

Quantitative data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 22.0 (Armonk, NY). Descriptive statistics and Chi-Square Test of Independence for nominal data and Kruskal-Wallis Tests for skewed data are reported. Data for categorical variables are reported as counts (N) and percentages (%). Medians and interquartile ranges (IQR) are reported for skewed data.

Participants’ responses to the qualitative, open-ended question were analyzed using ATLAS.ti, (Version 6.0; Dowling). The data were coded using the constant comparison content analysis technique (Miles, Huberman, & Saldana, 2013). An *a priori* list of codes was used and additional codes were added to the list as new codes emerged from the data.

RESULTS

Participant Characteristics

Three hundred and twenty individuals contacted the study office and expressed an interest to participate. All interested individuals were screened for eligibility and two-hundred eighty seven met inclusion criteria and were enrolled; 74% of those enrolled completed the study for a total of 213 participants (See Table 1).

Descriptive summaries of patients with lower limb lymphedema by lymphedema type are shown in Table 1. Four categories of participants by lymphedema type 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%). For the purpose of this paper, those with lower-leg lymphedema of unknown origin were not included in the analysis due to the ambiguity of lower-limb lymphedema. Statistically significant differences were observed between the secondary cancer-related, secondary non-cancer-related, and primary groups for gender, employment status, and lymphedema location (see Table 1). Participants were predominantly female (n=159, 89.3%), employed full-time (n=75, 42.1%), and with lymphedema in both legs (n=72, 40.4%).

Lymphedema Symptom Intensity and Distress Survey-Leg: Quantitative Analyses

Symptom prevalence—The majority of participants (≥ 65%) reported symptoms in the psycho-social domains: sadness (n=116, 65.9%), appearance concerns (n=145, 81.9%), loss of body confidence (n=120, 67.8%), fatigue (n=134, 75.7%), inability to do hobbies or leisure activities (n=116, 65.2%), and decreased physical activity (n=123, 69.5%). For insurance-related symptoms (i.e., insurance frustration and lack of confidence in insurance), less than 50% of participants expressed a lack of confidence in insurance and frustration with insurance. A statistically significant difference was found among the primary, cancer, and non-cancer groups in the lack of self-confidence ($\chi^2_{(df=2)} = 9.19$, $p = .010$) with the primary lymphedema group reporting the highest lack of self-confidence (see Table 2).

Symptom intensity and distress—Symptom intensity and symptom distress scores are reported in Table 3. The highest median s*ymptom intensity* score was reported for insurance-related symptoms: lack of confidence in insurance (Median=9.0, 25th and 75th IQR=7, 9) and insurance frustration (Median=8.5, 25th and 75th IQR=7, 10). A high median score of 8.0 was reported for “concerns about looks” (IQR=5, 10) and “loss of body confidence” (IQR=6, 9.5). When comparing symptom intensity scores across groups (i.e., secondary cancer-related, secondary non-cancer-related, and primary groups), patients in the cancer group reported the highest symptom intensity of 10.0 for insurance-related and social symptoms (see Table 4) and the highest symptom intensity of 9.0 for the psychological symptom “concerns about looks”. Patients in the cancer group reported the lowest median intensity score in the psychosocial domains for symptoms of “sadness”, “lack of self-confidence”, “anger”, and “less social activity”. However, no statistically significant differences were found in the reported *intensity* of psychological, social, and insurance-related symptoms or sub-scale scores between groups by lymphedema type.

The highest median *symptom distress* score of 8.0 was reported for symptoms “concerns about looks” (IQR=5, 10), “less physical activity” (IQR=5, 10), “loss of body confidence (IQR= 6, 10), “lack of self-confidence (IQR=5, 10), and “increased appetite” (IQR=5, 9.75). Patients in the cancer group reported the highest median score of 10.0 for insurance-related symptoms, as well as for “lack of interest in sex” (IQR=6, 10) and “partner lack of interest in sex” (IQR=2, 10). Compared to other two groups, the cancer group patients reported the lowest median scores for the psychological symptom of “sadness” (Median=5.5, IOR=2.75, 10), “lack of self-confidence” (Median=3.25, 10), and “anger” (Median=5.5, IQR=2.25, 9.75) and for the social symptom of “can’t do hobbies or leisure activities” (Median=6, IQR=5, 10). No statistically significant differences were found, however, in the reported *distress* of psychological, social, and insurance-related symptoms or sub-scale scores between groups by lymphedema type.

Qualitative Findings

One-hundred and thirty-eight participants responded to the qualitative, open-ended question. Four major themes emerged from the qualitative data: impacting psychosocial well-being, lacking resources, affecting physical and functional health, and treatment and self-care. The emerging themes were comparable across groups (i.e., primary and secondary cancer- and non-cancer related lower-limb lymphedema). Please refer to Electronic Supplemental Materials for supporting participant comments.

Impacting psychosocial well-being

Patients living with lower-limb lymphedema experience an altering body image that impacts their psychological and social well-being. Patients feel self-conscious about their appearance in front of others and feel the need to hide their legs and the compression garments. Their appearance is influenced by not finding formal or good looking and well-fitting clothes and shoes to accommodate their larger limbs and swollen feet. Patients reported various psychosocial symptoms due to having the disease. Patients reported feeling depressed, distressed, and anxious due to the uncertainty of their symptoms. They worry over compression garments becoming ineffective and getting infections. They expressed fear about their symptoms worsening and the impact of symptom accelerations on their activities. Several participants expressed their distress at people staring or asking questions related to the swelling in their limbs. Grieving is also experienced. As one participant stated: “There has and continues to be a grieving process over the losses.” Patients’ social well-being is also impacted by having the disease. Participants expressed the inability to participate in activities such as dancing and playing tennis, having difficulty traveling, and being tender to touch from others. Airline travel is challenging because of standing in lines and pain is more severe following travel. Avoiding being seen in public was also expressed by one participant: “*…*[I] will not go out in public unless I am made to most days.”

Lacking resources

Patients lack the financial resources, resources for clothing and shoes, and availability of lymphedema practitioners. Patients lack the financial resources for expenses related to compression garments and therapy. Participants in both the primary and secondary non-cancer related groups expressed financial difficulty for out-of-pocket payments for compression garments and bandages or to pay for clothing or having clothing altered to fit swollen limbs. The inability to pay for compression garments impacts their care. One participant’s words (cancer group) were striking: “ … because I’m in a position where I can’t afford to purchase anything that will help me or in a position where I can get any treatment at all. I am basically waiting for the antibiotics to not work and then I’ll die.” Participants are also financially impacted because their ability to work and maintain employment is reduced. A large number of participants across all group reported finding well-fitted clothes and shoes to accommodate the enlarged limb and swollen feet and finding compression garments or wraps.

Access to care is also problematic. Participants in all three groups expressed difficulty finding and gaining access to practitioners who are knowledgeable in lymphedema and its treatment. As one participant with primary lymphedema noted: “One of my biggest problems is being able to get in to a lymphdema [sic] therapist and then being able to continue treatment so that I can get this managed.”

Physical and functional impairments—Patients with lower-limb lymphedema, regardless of cause, reported physical consequences and functional impairments. Physical consequences (beyond swelling and heaviness) include infections (often repeatedly) such as cellulitis and infected spots on legs with subsequent hospitalizations and leg ulcers, scarring, blisters, and weeping skin or wounds. Drainage from wounds and skin is particularly problematic as it increases the frequency of self-care (i.e., frequent skin wrappings) that is time consuming and the need to add additional material for absorbency. As one participant noted:

> *It* [skin[cracked and I leak lymph fluid, … which means that I have the added joy of having to wear and change sanitary napkins, which I use for their absorbancy[sic], keeping that area wrapped in an ace bandage, which only adds to the bulk that I am already dealing with. Fun, fun, fun……..

One participant in the cancer group also reported the loss of flexibility and one participant with primary lymphedema noted: “A feeling that my leg is ‘dead’, does not belong to my body.” Participants associated some medical complications with having lymphedema: back spasms, burning foot pain, athlete’s foot, ingrown toenails, bursitis in hip, and exacerbation of tendinitis. Patients in the primary and secondary non-cancer groups also reported the exacerbation of other disease symptoms. For example, one participated noted: “I have two other conditions, neuropathy and Restless Legs Syndrome, that are triggered by the swelling.”

Functional impairments were also reported: doing activities of daily living, experiencing travel difficulties, finding well-fitted clothing and shoes, interrupting sleep, and impacting work. Participants in all groups reported difficulty dressing self, getting in and out of vehicles, and walking, standing, and swimming. Participants in the cancer-related secondary and primary lymphedema groups reported also interrupted sleep and difficulty working due to work-related activities such as sitting at a desk, which causes increased swelling, pain and discomfort.

Treatment and care—Participants in all groups reported treatment-related and care-related (care by others and self-care) problems and challenges. Treatment-related problems include compression garments causing problems such as feeling hot, causing open sores, and intense pain from garments cutting into their skin. Wearing compression garments also adds to the difficulty of finding clothing to wear over garments. One participant associated wearing compression hose with the bottom of her feet becoming “*misshapen and hardened*”.

Lacking knowledge of treatment options was mentioned by one participant with primary lymphedema. Despite having had primary lymphedema for “*a long time”,* this participant only recently learned about Manual Lymph Drainage, suggesting that participants with lymphedema may not be aware of available treatment options. Receiving quality care is also a significant problem. Participants in the primary group reported that the quality of care in the lymphedema system of care is lacking and that lymphedema care as fragmented. Some participants reported the occurrence of a delayed diagnosis of lymphedema due to an unknowledgeable general practitioner who failed to make the diagnosis. The participant with the delayed diagnosis commented: "I have discovered that most doctors are incredibly ignorant when it comes to lymphedema." In contrast, some participants reported the support and education provided by the physical therapist trained in lymphatic massage. Participants also reported managing self-care as burdensome. Weeping skin and wounds requires increased time for self-care because of the higher frequency of skin wrapping that is needed daily, and wrapping the skin is time-consuming. As one participant noted: "Self-treatment takes a couple of hours each night which is burdensome."

DISCUSSION

Quantitative Findings

This is the first study the authors are aware of to investigate differences in the psychosocial impact of lower-limb lymphedema by *lymphedema type.* Previous studies have compared patients with and without lower-limb lymphedema (Cromwell et al., 2015) and patients with unilateral and bilateral lower-limb lymphedema (Deng et al., 2015). Studies have also demonstrated the impact of lower-limb lymphedema on the psycho-social well-being of patients with primary and cancer-related lower-limb lymphedema (Fu & Kang, 2013; Cromwell et al., 2015; Dunberger et al., 2013; Novackova et al., 2012; Deng et al., 2013, 2015). However, the majority of studies examining psychosocial functioning in patients with lower-limb lymphedema focus on those with cancer-related secondary lower-limb lymphedema (Fu & Kang, 2013; Cromwell et al., 2015; Dunberger et al., 2013; Novackova et al., 2012; Deng et al., 2015). In contrast, this study described and compared psychosocial functioning in three groups of participants: secondary cancer- and non-cancer related groups and a primary lymphedema group. Participants in this study reported a higher prevalence (> 65%) of psychosocial symptoms compared to previous reports (20 to 27%). Similar to reports of patients with cancer-related lower-limb lymphedema feeling less attractive, have unmet sexual needs, and avoid social activities and meeting friends, (V. Beesley et al., 2007; Dunberger et al., 2013), this study found that patients with *non-cancer* related secondary and those with primary lymphedema also experience less social activities, an inability to do hobbies or leisure activities, and less sexual activity.

The study also found that patients with primary and secondary (cancer and non-cancer related) lower-limb lymphedema experienced high levels of *intensity and distress* for symptoms in the psychosocial domains and related to insurance. Patients experienced the highest intensity and distress for symptoms related to insurance. Patients also experience a high intensity for symptoms in the psychological domain related to body image (i.e., "concerns about looks" and "loss of body confidence"), but higher scores are somewhat more frequent for social domain symptoms with highest intensity reported for activities ("i.e., hobbies/leisure and social) and sexual functioning (i.e., feeling less sexually attractive). Thus, patients with lower-limb lymphedema experience psychosocial sequela and sexual dysfunction similar to what has been reported for patients with upper-limb lymphedema. (McWayne & Heiney, 2005) Studies have reported psychosocial sequela from having lower-limb lymphedema in patients with secondary cancer-related lymphedema (Finnane et al., 2011; McWayne & Heiney, 2005) and patients with primary lower-limb lymphedema (Symvoulakis et al., 2010). This study, however, included patients with secondary non-cancer related lower-limb lymphedema and demonstrate that these patients also experience psychosocial sequela from the disease.

The findings of this study are comparable to other studies that have reported social and sexual dysfunction in patients with lower-limb lymphedema secondary to cancer. (V. Beesley et al., 2007; Finnane et al., 2011) Specifically, when comparing groups, the cancer group patients reported the highest intensity and distress scores (Median score ≥ 8.5) for several symptoms, particularly symptoms related to insurance and social functioning related to sexual activity and attractiveness, compared to the non-cancer secondary lymphedema and primary lymphedema groups. This study, however, also demonstrates that patients with cancer-related lower-limb lymphedema experience frustration with their insurance and lack of confidence in their insurance.

The psychological impact of lower-limb lymphedema has been reported in patients with cancer-related lymphedema and includes changes to body image and self-esteem, feelings of helplessness, fear and worry about disease progression.(Finnane et al., 2011; McWayne & Heiney, 2005; Symvoulakis et al., 2010) This study found that when compared to other groups and with the exception of “concerns about looks”, the cancer group patients reported lower median scores for the majority of psychological symptoms (Median ≤ 6.5). The intensity and distress of psychological symptoms appear to be experienced to a higher degree by those with primary and non-cancer related secondary lymphedema. Studies comparing symptoms of those with primary and secondary lower-limb lymphedema have found that those with primary lower-limb lymphedema reported higher overall health and quality of life than those with secondary lower-limb lymphedema. (Huggenberger et al., 2015) However, the researchers did not differentiate between those with secondary cancer-related versus non-cancer related lower-limb lymphedema. This study demonstrates that patients with cancer-related versus non-cancer related secondary lower-limb lymphedema expressed differences in symptom intensity and distress.

Qualitative Findings

Patient’s qualitative comments indicated that differences in psychosocial and insurance-related symptoms between the three groups were rare. Participants reported psychosocial symptoms and their comments shed some light on potential reasons for reported psychosocial symptoms. As demonstrated by other studies, (Brown et al., 2013; Dunberger et al., 2013; Finnane et al., 2011; McWayne & Heiney, 2005) living with lower-limb lymphedema impacts the psychosocial well-being of patients and causes physical and functional impairments. An alternation in body image results from appearance concerns and inability to find well-fitting clothes and shoes. Patients feel worried, distressed and anxious, and fear that the compression garments will become ineffective. They are acutely aware of people staring and asking questions. Their social well-being is impacted by their inability to participate in some activities and travel, leading to social isolation. The physical and functional impairments further contribute to the social isolation and psychological symptoms. Physical impairments reported include repeated infections, hospitalizations, and physical consequences (i.e., leg ulcers, scarring and weeping skin). Similar to other studies, (Brown et al., 2013)patients with lower-limb lymphedema also experience difficulty completing activities of daily living and activities such as walking, standing, and swimming. This finding is congruent with others who have reported that patients with lower-limb lymphedema were five-fold more likely to report poor physical function when compared with those without lower-limb lymphedema. In addition, those with primary and cancer-related lymphedema also reported lack of sleep and difficulty working.

Patients with lower-limb lymphedema lack resources and experience treatment and care-related challenges like the lack of financial resources and the availability of clothing and shoes. Particularly alarming is the reported issues with access to care and practitioners who are knowledgeable of lymphedema and its treatment. Finanne and colleagues (2011) previously reported dissatisfaction with “health system processes” (p.293) by those with cancer-related secondary lymphedema. This study, however, found that access to care and knowledgeable practitioners were problematic for patients with primary, secondary cancer-related, and secondary non-cancer related lymphedema. Future research studies are needed to explicate reasons for barriers to care and to develop interventions addressing barriers to care and to enhance practitioner knowledge and access to care.

Patients with lower-limb lymphedema also reported fragmented care and delayed lymphedema diagnoses because of unknowledgeable primary care providers. For instance, a delayed diagnosis occurred only when symptoms became severe and a second opinion was sought by the patient. Others have reported similar problems with the identification and diagnosis of lymphedema. In a case study of two patients with primary lower-limb lymphedema, Symvoulakis and colleagues (2010) noted that the lack of physicians’ awareness of the disease resulted in a patient suffering for an extended period of time without a diagnosis. Brown et al. (2013) similarly found undiagnosed lower-limb lymphedema in 18% of patients (N=17) with cancer-related lymphedema. Diagnosing lower-limb lymphedema may be problematic or delayed because limb swelling may be (wrongly) attributed to deep vein thrombosis or congestive heart failure. Individuals with persistent lower-limb swelling should consult with their health care providers and seek the help of practitioners specialized in lymphedema. Future studies are needed to investigate and find solutions to improve practitioners’ knowledge on lymphedema and to reduce the risk of misdiagnoses.

Additional treatment and care symptoms were also reported. Similar to reports of patients with upper-limb lymphedema struggling with time management and difficulty completing self-care and interrupted sleep, (Ridner, 2009), patients with lower-limb lymphedema similarly report interrupted sleep and burdensome self-management because of the time required to do the wrappings. Knowledge of treatment options and problems with compression garments (i.e., feeling hot, causing open sores, and pain) and the burdensome self-management that the disease requires were also reported.

Some limitations to the study must be acknowledged. Recruitment strategies were limited and not all patients with lower-limb lymphedema may have been made aware of the study. Also, because only participants that have been diagnosed with lower-limb lymphedema were included, it is plausible that this study only include participants with more sever lower-limb lymphedema, therefore the data may not be representative of the population of patients with lower-limb lymphedema. The use of a self-report survey increased the risk for response bias. However, steps that were taken to reduce this risk included informing patients of the confidentiality of their responses and the reporting of data in the aggregate only. Because the qualitative analysis was limited to the comments that participants volunteered, sampling to achieve data saturation was not possible. However, a large number of participants provided in-depth comments (n=138) and allowed for the identification of patterns and categories in the data to support the qualitative findings.

In sum, patients with lower-limb lymphedema experience different symptoms related to psychosocial well-being and insurance-related symptoms, regardless of lymphedema type.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Descriptive statistical summaries of the study groups

	Secondary N(%)		Primary N(%)	Total N (%)	p-value[*]
	Cancer	Non-Cancer			
Total by Group	37 (20.8)	45 (25.3)	96 (53.9)	178 (100)	
Gender					.039
Male	1 (2.7)	3 (6.7)	15 (15.6)	19 (10.7)	
Female	36 (97.3)	42 (93.3)	81(84.4)	159 (89.3)	
Race					.199
White	34 (91.9)	40 (88.9)	80(83.3)	154(86.5)	
Black	3 (8.1)	2 (4.4)	9(9.4)	14 (7.9)	
Other	0 (0)	3 (6.7)	7(7.3)	10 (5.6)	
Ethnic group					.070
Hispanic or Latino	3 (8.1)	0 (0)	6(6.5)	9 (5.2)	
Not Hispanic or Latino	34 (91.9)	42 (100)	87(93.5)	163 (94.8)	
Marital Status					.327
Single	8 (21.6)	10 (22.2)	19(19.8)	37 (20.8%)	
Married or Living with partner	27 (72.9)	32 (71.1)	67(69.8)	126 (70.8)	
Widowed	1 (2.7)	3 (6.7)	3(3.1)	7 (3.9)	
Other	1 (2.7)	0 (0)	7(7.3)	8 (4.5)	
Employment Status					.038
Employed Full-time	17 (45.9)	17 (37.8)	41(42.7)	75 (42.1)	
Employed Part-time	6 (16.2)	9 (20)	9(9.4)	24 (13.5)	
Homemaker	0 (0)	4 (8.9)	4(4.2)	8 (4.5)	
Unemployed	0 (0)	3 (6.7)	12(12.5)	15 (8.4)	
Retired	10 (27)	9 (20)	16(16.7)	35 (19.7)	
Insurance Coverage					.261
Medicare	12 (32.4)	9 (20.5)	17(18.1)	38 (21.7)	
Medicaid	1 (2.7)	2 (4.5)	6 (6.4)	9 (5.1)	
Private Insurance	14 (37.8)	17 (38.6)	31(33.0)	62 (35.4)	
HMO	5 (13.5)	4 (9.1)	17(18.1)	26(14.9)	
None	0 (0)	4 (9.1)	2(2.1)	6(3.4)	
Other	5 (13.5)	8 (18.2)	21(22.3)	34(19.4)	
Lymphedema Location					.000
Left leg	11 (29.7)	15 (33.3)	12(12.5)	38 (21.3)	
Right leg	8 (21.6)	11 (24.4)	12(14.6)	33 (18.5)	
Both legs	7 (18.9)	10 (22.2)	55(57.3)	72 (40.4)	
Leg and abdomen/groin	6 (16.2)	2 (4.4)	5(5.2)	13 (7.3)	
Both legs and abdomen/groin	5 (13.5)	7 (15.6)	10(10.4)	22 (12.4)	

[*] Likelihood Ratio

Table 2

Group Differences in Psycho-social Symptom Frequency.

	Secondary N(%)		Primary N (%)	Total N (%)	p-values
	Cancer	Non-cancer			
Total by Group	37 (17)	45 (21)	96 (45)	178(100)	
Sadness					.555
No	14(21.2)	17(25.8)	29(43.9)	60 (34.1)	
Yes	22(15.3)	28(19.4)	66(45.8)	116 (65.9)	
Anger					.746
No	20(18.0)	22(19.8)	53(47.7)	95 (53.7)	
Yes	17(17.2)	23(23.2)	42(42.4)	82(46.3)	
Lack of self-confidence					.010
No	25(26.6)	16(17.0)	41(43.6)	82 (46.6)	
Yes	12(10.3)	29(25.0)	53(45.7)	94(53.4)	
Lack of confidence in insurance					.855
No	19(16.1)	25(21.2)	55(46.6)	99 (56.9)	
Yes	17(19.1)	18(20.2)	40(44.9)	75(43.1)	
Concerns about looks					.310
No	10(27.0)	7(18.9)	15(40.5)	32(18.1)	
Yes	27(15.4)	38(21.7)	80(45.7)	145(81.9)	
Misunderstood by S.O.					.185
No	30(20.0)	30(20.0)	62(41.3)	122(69.3)	
Yes	7(11.5)	14(23.0)	33(54.1)	54(30.7)	
Less sexually attractive					.113
No	14 (23.7)	7 (11.9)	32(54.2)	53(30.1)	
Yes	16 (13.8)	30 (25.9)	46 (39.7)	92(52.3)	
Prefer not to answer	6(16.7)	8(22.2)	17(47.2)	31(17.6)	
Insurance frustration					.426
No	24(19.0)	23(18.3)	56(44.4)	103(58.9)	
Yes	12(14.3)	21(25.0)	39(46.4)	72(41.1)	
Lost body confidence					.432
No	15(21.7)	12(17.4)	30(43.5)	57(32.2)	
Yes	22(15.5)	32(22.5)	66(46.5)	120(67.8)	
Fatigue					.210
No	12(23.5)	7(13.7)	24(47.1)	43(24.3)	
Yes	25(15.5)	37(23.0)	72(44.7)	134(75.7)	

	Secondary N(%)		**Primary N (%)**	**Total N (%)**	**p-values**
	Cancer	**Non-cancer**			
Difficulty sleeping					.233
No	20(19.0)	17(16.2)	49(46.7)	86(48.6)	
Yes	17(15.9)	28(26.2)	46(43.0)	91(51.4)	
Increased appetite					.750
No	27(17.1)	32(20.3)	74(46.8)	133(75.1)	
Yes	9(17.0)	13(24.5)	22(41.5)	44(24.9)	
Lack interest in sex					.602
No	15(14.6)	17(16.5)	48(46.6)	80(45.7)	
Yes	15(21.4)	18(25.7)	30(42.9)	63(36.0)	
Prefer not to answer	5(13.5)	9(24.3)	18(48.6)	32(18.3)	
Partner lack of interest in sex					.897
No	23(18.4)	27(21.6)	52(41.6)	102(58.3)	
Yes	5(15.2)	8(24.2)	16(48.5)	29(16.6)	
Prefer not to answer	8(16.0)	10(20.0)	26(52.0)	44(25.1)	
Can’t do hobbies or leisure activities					.613
No	14(19.2)	13(17.8)	35(47.9)	62(34.8)	
Yes	23(16.4)	32(22.9)	61(43.6)	116(65.2)	
Less social activities					.395
No	23(21.7)	22(20.8)	47(44.3)	92(52.3)	
Yes	14(13.3)	22(21.0)	48(45.7)	84(47.7)	
Less physical activity					.580
No	12(19.0)	11(17.5)	31(49.2)	54(30.5)	
Yes	24(16.1)	34(22.8)	65(43.6)	123(69.5)	
Less sexual activity					.886
No	14(15.4)	16(17.6)	43(47.3)	73(41.5)	
Yes	13(18.1)	18(25.0)	32(44.4)	63(35.8)	
Prefer not to answer	8(17.4)	11(23.9)	21(45.7)	40(22.7)	

* Likelihood Ratio.

Table 3

Descriptives for Symptom Intensity and Distress.

Symptom	**Symptom prevalence % (Overall)**	**Symptom Intensity Median [IQR]**	**Symptom Distress Median [IQR]**
Concerns about looks	81.9	8[5,10]	8[5,10]
Fatigue	75.7	7[5,8]	7[4,8]
Less physical activity	69.5	7[5,9]	8[5,10]
Lost body confidence	67.8	8[6,9.5]	8[6,10]
Sadness	65.9	6[4,9]	7[3,9]
Can’t do hobby or leisure activities	65.2	8[5,9]	8[6,10]
Lack of self-confidence	53.4	7[5,7]	8[5,10]
Less sexually attractive	52.3	8[6,10]	8[5,10]
Difficulty sleeping	51.4	7[4.75,8]	7[4,9]
Less social activity	47.7	8[6,10]	8[6,10]
Anger	46.3	6[4,8]	6[4,8]
Lack of confidence in insurance	43.1	9[7,9]	9[7,10]
Insurance frustration	41.1	8.5[7,10]	9[8,10]
Lack interest in sex*	36.0	7[5,10]	7[5,10]
Less sexual activity	35.8	7[5,10]	7.5[5,9]
Misunderstood by SO	30.7	7[5,8]	7[5,10]
Increased appetite	24.9	7[5,8]	8[5,9.75]
Partner lack of interest in sex	16.6	7[4,10]	7[5,10]

** $p \geq .01$

[*] $p < .05$;

Table 4

Descriptives of Psychosocial Symptom Intensity and Distress by Groups.

Symptom	**Symptom prevalence**	**Symptom Intensity Median [IQR]**			**p-value**	**Symptom Distress Median [IQR]**			**p-value**
	N (%)	**Secondary**		**Primary**		**Secondary**		**Primary**	
		Cancer	**Non-cancer**			**Cancer**	**Non-cancer**		
Psychological Symptoms									
Concerns about looks	144 (81.9)	9 [5,10]	8 [6,10]	8 [5,10]	.558	8 [5,10]	8 [5,10]	8 [5,10]	.797
Fatigue	134 (75.7)	6 [4,7.5]	7 [5,8]	7 [5,8]	.323	7 [2.5,8]	7 [4,8]	7 [5,8.9]	.699
Less physical activity	123 (69.5)	7 [3,8]	8 [5.8,9.3]	7 [5,9]	.221	6.5 [3,10]	8 [5,9.5]	8 [6,10]	.322
Lost body confidence	117 (67.8)	8 [6.3,10]	8 [6,10]	7 [5,9]	.340	8 [5,10]	8 [6.3,10]	7 [6,10]	.686
Sadness	115 (65.9)	5 [3,10]	7 [5,9]	6 [4,8]	.395	5.5 [2.8,10]	8 [5,10]	7.5 [3,8.3]	.269
Lack of self-confidence	94 (53.4)	4.5 [2.3, 9.5]	8 [6,9]	7 [5,9]	.793	6 [3.3,10]	8 [5,10]	8 [5,10]	.521
Difficulty sleeping	90 (51.4)	7 [4,8]	8 [6,9]	6.5 [4,8]	.184	7 [4,10]	8 [5,9.8]	6 [4,8.5]	.351
Anger	82 (46.3)	5 [3.5,9.5]	6 [5,9]	6 [4,7.3]	.643	5.5 [2.3,9.8]	6 [4,9]	6 [3.8,8]	.939
Increased appetite	43 (24.9)	8 [5,10]	6.5 [5,7.8]	6 [5,8]	.361	10 [3,10]	7 [5.5,9]	7.5 [5,9.8]	.657
Insurance-related Symptoms									
Lack of confidence in insurance	75 (43.1)	10 [5.5,10]	8.5 [7.5,10]	8.5 [7,10]	.994	10 [6,10]	8 [7.5,10]	9 [7,10]	.887
Insurance frustration	72 (41.1)	10 [8,10]	8 [7,10]	8 [7,10]	.603	10 [8,10]	9 [7,10]	9 [8,10]	.735
Social Symptoms									
Can’t do hobby/ leisure activities	116 (65.2)	6 [4,8]	8 [5.3,9.8]	8 [6,9.5]	.179	6 [5,10]	8.5 [6,10]	8 [7,10]	.369
Less sexually attractive	91 (52.3)	8.5 [4.5,10]	8 [6,9]	8 [5.8,10]	.771	7.5 [3.5,10]	7.5 [5.8, 10]	8 [4.5,10]	.959
Less social activity	83 (47.7)	6.5 [4.8,10]	8 [7,10]	8 [6,9]	.244	7 [5,10]	8.5 [7,10]	8.5 [6.3,10]	.811
Lack of interest in sex	61 (36.0)	10 [6,10]	8 [6,10]	6 [5,8]	.057	8 [5,10]	6 [1,8.3]	6.5 [4.8,10]	.211
Less sexual activity	61 (35.8)	8.5 [5.3,10]	8 [5,9.5]	7 [5,8.8]	.678	7 [4,10]	7.5 [5,9]	8 [6,10]	.820
Misunderstood by SO	53 (30.7)	7 [1,8]	7 [5,9]	6.5 [5,8]	.829	8 [1,10]	7 [5.5,10]	7 [5,9]	.942
Partner lack of interest in sex	29 (16.6)	10 [2,10]	6.5 [4,9.5]	7.5 [5,10]	.807	10 [5.5,10]	6 [4.3,7.5]	7 [5.5,9.8]	.163

Note. p-values for Kruskal-Wallis tests reported. Level of significance set at p <.05; SO = Significant Other