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Patient-Reported Outcome Measures of Function and Quality of Life in Individuals with Lower Extremity Lymphedema: A Scoping Review

Rachel A. Dratnol
Rush University - USA, rachel.dratnol@gmail.com

Laura H. VanPuymbrouck
Rush University - USA, Laura_vanpuymbrouck@rush.edu

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Patient-Reported Outcome Measures of Function and Quality of Life in Individuals with Lower Extremity Lymphedema: A Scoping Review

Abstract

Background: Lower extremity lymphedema (LEL) is more prevalent than lymphedema in other body parts. Assessing lymphedema severity and impact on occupational functioning and quality of life (QOL) is essential to client-centered care in occupational therapy. The purpose of this study was to identify and compare the patient-reported outcome measures (PROMs) available to assess QOL and/or level of functioning in individuals with LEL and studies using such assessments.

Method: A search of two online databases (PubMed and CINAHL) yielded 15 studies. A scoping review was completed.

Results: Numerous PROMs were identified in the development and/or validation studies or used in impact studies, with general QOL and functional assessments rather than disease-specific assessments used more frequently.

Conclusion: Further work is needed to use disease-specific QOL and functional evaluation tools in the assessment of lymphedema severity and impact. This scoping review identifies the available PROMs for assessing people with LEL and underlines why occupational therapists should be using them to assess their clients.

Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

lymphedema, lower extremity, quality of life, patient reported outcome measures

Cover Page Footnote

Thank you to Reina Williams, manager of research and instruction at the Library at Rush University Medical Center, for her assistance with completing the literature search for this scoping review.

Credentials Display

Rachel A. Dratnol, MOT, OTR/L, CLT

Laura H. VanPuymbrouck, PhD, OTR/L

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Swelling occurs when fluid accumulates in the interstitial space immediately under the skin (Lymphoedema Framework, 2006). Edema, the medical term for swelling, is characterized by its low protein and high-water content and as a symptom of another problem, such as infection, the consequence of taking medications, and acute injury, among other issues. Addressing these causes can eliminate edema. Lymphedema, on the other hand, is a chronic and progressive condition where tissues swell with protein-rich fluid following a failure of the lymphatic system to remove excess interstitial fluid. Lymphedema is its own diagnosis and does not currently have a cure (Lymphoedema Framework, 2006). It is classified as either primary, stemming from a congenital malformation of the lymphatic system, or secondary, acquired later in life after some form of trauma to the lymphatic system (Lymphoedema Framework, 2006; Weissleder & Schuchhardt, 2008). This scoping review identifies and compares patient-reported outcome measures (PROMS) of quality of life (QOL) and/or level of functioning in individuals with lower extremity lymphedema (LEL) and describes studies using such assessments. This review describes the causes of LEL, occupational therapists' role in working with clients with LEL, and the importance of including QOL and occupational performance in assessment. This overview is followed with a summary of the literature that can inform assessment and intervention design with this client group.

Lymphedema

Lymphedema in all its forms has long been underrecognized, underdiagnosed, and, consequently, undertreated, especially in the lower extremities (LEs) (Keast et al., 2014). This results from limited public awareness, insufficient knowledge in the health care community, and poor reimbursement and coverage of medical care (Keast et al., 2014; Stout et al., 2013). Lymphedema is most commonly found in the LEs in comparison with other areas of the body, including the upper extremities (UEs), head and neck, abdomen, and genitals (Devoogdt et al., 2014; Ridner et al., 2018). LEs are classified as “anything below the navel” and include the lower abdomen, hips, buttocks, genitals, thighs, knees, lower legs, calves, and feet (Yost et al., 2013, p. 695).

Lymphedema has numerous causes, including but not limited to cancer, chronic venous insufficiency, obesity, and trauma (Keast et al., 2019; Wang & Keast, 2016). In developed countries, cancer and its treatment have long been considered the most common cause of secondary lymphedema in the UEs and LEs. However, chronic venous insufficiency was more recently found to be a more prevalent cause of LEL in 41.8% of cases, followed by cancer in 33.9% (Dean et al., 2019).

Differing Impact of Upper Versus LEL

Upper extremity lymphedema (UEL), especially after breast cancer and its treatment, has been extensively studied (Bojinović-Rodić et al., 2016; Can et al., 2019). Studies of LEL and its impact on function and QOL remain sparse in comparison. The direct transfer of information from UEL to LEL is not appropriate because of the differences in size, volume, location, skin changes, and function between the UEs and LEs (Devoogdt et al., 2014). LEL is more evenly distributed between males and females. Further, more individuals with LEL have bilateral involvement and more complex lymphedema, including increased prevalence of wounds and infection and self-reported limb heaviness and skin tightness (Keast et al., 2019; Wang & Keast, 2016; Yost et al., 2013). Better treatment outcomes occur when a person with any chronic condition, including lymphedema, is diagnosed and receives treatment as early as possible. However, when diagnosed, individuals with LEL are often in the condition's more advanced stages, further impeding positive outcomes of the treatment they may receive (Wang & Keast, 2016).

Occupational Therapy’s Role in the Treatment and Management of Lymphedema

There is no cure for lymphedema; it can only be managed once diagnosed and will progress without treatment (Lymphoedema Framework, 2006). Complete decongestive therapy (CDT), the gold standard of conservative treatment of lymphedema, is recommended to be completed with a certified lymphedema therapist (CLT) (Anderson et al., 2019). Occupational therapists are some of the health care professionals who may further train to become CLTs (Dominick et al., 2014) and represent approximately 30% of all CLTs (Anderson et al., 2019).

CDT follows the acute medical model of disease treatment (Rubio, 2018; Shier, 2012). Unlike other professionals who may also train as CLTs, occupational therapists integrate CDT with holistic, client-centered practice and chronic disease management models (Rubio, 2018; Shier, 2012). They are well-suited to address the functional, physical, and psychosocial difficulties, including “hidden resources, such as motivation” that often accompany a lymphedema diagnosis (Mayers, 1995, p. 150), and use CDT together with chronic condition management techniques to improve a client’s QOL (Shier, 2011, 2012).

Occupational therapists aim to assess and improve a client’s QOL at evaluation and throughout treatment (Mayers, 1995). Clients may be better able to adapt and improve their QOL when working with an occupational therapist (Mayers, 1995). Specifically, regarding treatment for lymphedema, occupational therapists empower their clients to care for and manage their lymphedema in the long-term. They do so through (a) educating clients regarding the chronicity of lymphedema, (b) improving motivation to complete self-management, (c) assisting clients in developing new routines to incorporate their lymphedema self-management program into their daily life, (d) improving skin care routines, (e) issuing and educating clients regarding best exercise routines, and (f) educating and practicing self-manual lymphatic drainage techniques compliance (Douglass et al., 2016; Rubio, 2018; Shier, 2012). They help clients adjust previously acquired habits to minimize the risk of disease progression and modify home environment set-up. They also assess a client’s ability to don and doff recommended compression garments themselves and modify the technique as needed through adapted techniques, use of adaptive equipment, or with caregiver assistance to ensure compliance (Rubio, 2018).

Impact of Lymphedema on Function and QOL

UEL and LEL decrease a person’s QOL. Both increase employment difficulties, impair an individual’s ability to complete activities of daily living and instrumental activities of daily living, and prohibit participation in preferred leisure activities (Devoogdt et al., 2011; Devoogdt et al., 2014; Viehoff et al., 2015; Wang & Keast, 2016; Weiss & Daniel, 2015, 2018). In the LEs specifically, lymphedema further causes gait dysfunction, sexual problems, and mobility deficits with difficulty with prolonged sitting, standing, walking, driving a car, or riding a bike (Devoogdt et al., 2014; Viehoff et al., 2015; Wang & Keast, 2016). Assessing lymphedema severity and impact on occupational functioning and QOL is essential to the client-centered care occupational therapists provide (Lymphoedema Framework, 2006).

Objective severity of lymphedema is measured in several ways, such as staging, tape measurement, water volumetry, and bioimpedance (Hidding et al., 2016; Lee et al., 2018). However, no objective measurement is considered the gold standard for lymphedema severity, and they fail to depict the full impact of lymphedema on QOL (Hidding et al., 2016; Lee et al., 2018; Weiss & Daniel, 2018). People with moderate-severe lymphedema report high levels of QOL (Lee et al., 2018). A person’s subjective experience is not correlated to lymphedema severity and should also be measured for a holistic evaluation (Weiss & Daniel, 2015).

Patient-Reported Outcome Measures

Patient-reported outcome measures (PROMs) include any outcome measure directly reported by a client (Bottomley et al., 2019). Answers are collected via self-report or a recorded interview and provide increased insight into a person's perceptions. PROMs assess an assortment of outcomes, including QOL. QOL PROMs were developed in recognition of the subjective aspects of health and how treatment and management for chronic conditions may impact QOL over time (Bullinger & Quitmann, 2014). Health-related QOL refers to how a client perceives the effect of their condition and its treatment on the physical, psychological, and social aspects of their lives (Bottomley et al., 2019). Measuring QOL with PROMs is an important component of client-centered care for occupational therapists, including with clients with LEL (American Occupational Therapy Association [AOTA], 2020). The outcomes occupational therapists aim to achieve include occupational performance and participation, health and wellness, QOL, role competence, and occupational justice (AOTA, 2020).

Numerous PROMs exist to measure the impact of UEL on QOL, and UEL is more frequently studied (Devooght et al., 2011; Devooght et al., 2014). Commonly used PROMs addressing UEL include the generic 36-Item Short Form Health Survey (SF-36); oncology-specific questionnaires, including the Functional Assessment of Cancer Therapy-Breast (FACT-B), the European Organization for Research and Treatment of Cancer Questionnaire (EORTC), and the Functional Living Index-Cancer (FLIC) measures; and lymphedema-specific measures, including the Lymphoedema Quality of Life Study (LYMQOL) questionnaire (Fish et al., 2020). Fish et al.'s systematic review (2020) found significant, positive changes in health-related QOL following both surgical and non-surgical treatment. Other more UEL-specific PROMs have been developed, such as the Upper Limb Lymphedema Quality of Life (ULLQoL) (Williams et al., 2018) and the Lymphoedema Functioning, Disability, and Health Questionnaire (Lymph-ICF) (Devooght et al., 2011), but they have not been used frequently in further research beyond their validation studies, as of this publication.

Current understanding of how and which PROMs occupational therapists use with clients with LEL to identify the impact of intervention effectiveness is under-reported in the literature (Devooght et al., 2014; Weiss & Daniel, 2015). Understanding which, if any, PROM researchers prefer may establish validity for clinicians to incorporate this PROM into intervention assessment when working with clients with LEL.

PROMs of QOL and level of functioning used along with more objective measurements will provide a clearer description of the full impact of LEL (Haesler, 2015). The purpose of this scoping reviews was to determine the availability and scope of evidence, clarify definitions, assess how research is conducted on specific topics, identify prominent concept characteristics, determine need for a systematic review, and investigating knowledge gaps in the literature (Munn et al., 2018). The purpose of this paper was to complete a scoping review to identify and compare specific PROMs of QOL and/or the level of functioning in individuals with LEL and studies using such PROMs.

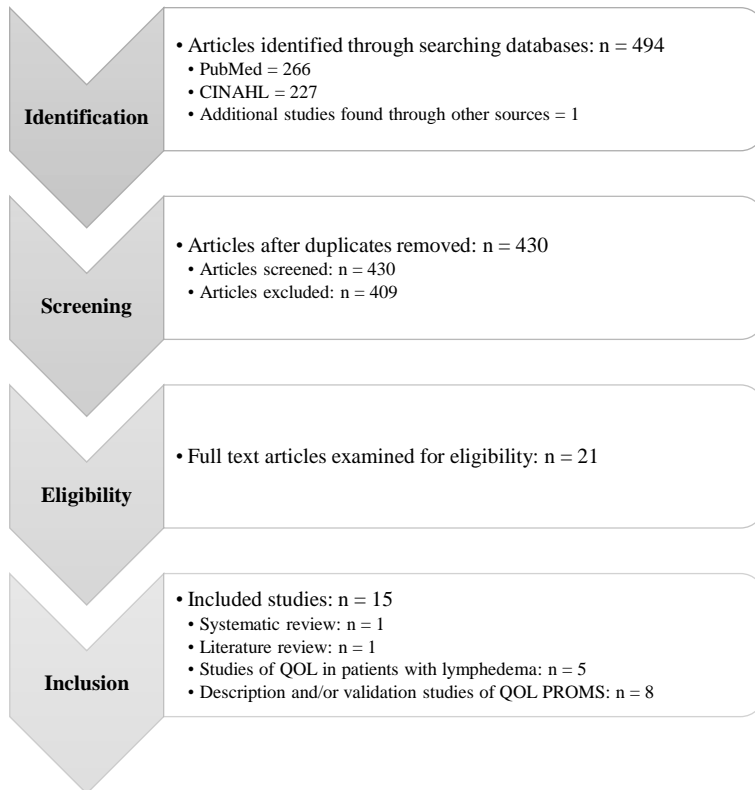
Method

The scoping review methodology was chosen because it allows for a broad view of the literature and assists in identifying gaps. The checklist from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR; Peters et al., 2015) guided the process (see Figure 1). PubMed and CINAHL databases were searched from January 1990 through December 2019. The following search terms were used: (lymphedema OR lymphoedema OR "chronic edema" OR "chronic oedema") AND ("lower extremity" OR "lower limb" OR leg) AND (function OR activity OR

occupation) OR “quality of life”) AND (assess* OR eval* OR screen* OR tool) NOT (“upper extremity” OR “upper limb” OR arm) NOT (head OR neck) NOT filariasis. These searches were also supplemented with a manual review of articles found in the searches.

Figure 1

Diagram for Scoping Review following PRISMA Guidelines



The researchers identified English language, full-text articles identifying or using PROMs of LEL to measure QOL or level of functioning. Articles were excluded if they were not published in English, described PROMs used to assess QOL or function only in participants with non-LEL, studied children as the primary population, or represented symptom and/or diagnostic subjective or objective assessments. Further, articles in abstract or poster presentation form also were excluded. The inclusion criteria were development and validation studies for new PROMs of lymphedema affecting either the UEs or LEs or only the LEs; validation studies of previously developed PROMs to now be used for clients with LEL; results describing lymphedema’s impact on the level of functioning, participation in preferred occupations, and QOL; and results describing other assessments to measure disability, QOL, and function.

For this scoping review, lymphedema is defined as swelling present for longer than 3 months in an extremity. People presenting with swelling shorter than 3 months may be included if they have a precipitating factor, such as a cancer diagnosis and treatment (Franks et al., 2006). The researchers located 494 articles originally, and 15 ultimately met the inclusion criteria.

Results

Numerous PROMs were identified in the articles regarding the assessment and measurement of LEL; however, the majority of these were targeting specific deficit areas or functioning or impairment, not QOL. Table 1 shows the characteristics of the included studies.

Table 1

Summary of Studies of PROMs used with People with LEL

Citation	Purpose	n	Study Type	Results	PROM Used
Carter et al., 2019	Estimate the incidence of LEL and identify the risk factors associated with the development of LEL in patients undergoing surgery for gynecologic cancer. Explore the predictive value of the GCLQ in identifying patients at risk for early-onset LEL.	914	Multi-institutional prospective study	The GCLQ identifies people with LEL and demonstrates a predictive value of PROM LLE symptom assessment in people at risk for developing LEL. GCLQ score change was frequently noted in the visit prior to the diagnosis of LEL.	GCLQ LEFS
Cemal et al., 2013	Complete a systematic review of HRQOL studies in patients with LEL to summarize the known literature on the effects of lymphedema.	6 Articles Sample sizes: 10–164	Systematic review	Four of the six studies evaluated the impact of treatment, and most did not conform to guidelines set for assessment HRQOL	MOS-Short Form McGill questionnaire WHO-ICF SF-36 FACT-G -QLQ-30 IDI-ILA part II
Devooght et al., 2014	Develop and assess the validity and reliability of the Lymph-ICF-LL.	Development: 20 Reliability & validity: 30	Reliability and validity study	The Lymph-ICF-LL is a reliable and valid Dutch questionnaire for assessing problems in functioning in people with LEL.	Lymph-ICF-LL SF-36
Franks et al., 2006	Examine the use of a number of tools in the evaluation of HRQOL in people with LLE.	Main Study: 228 QOL Questionnaires: 164 Follow-up questionnaire: 120	Epidemiology of lymphedema	For people with LEL, perceived improvements in health associated with greater physical functioning, and general health, but not pain. Chronic edema in the LELs has a major impact on patients' HRQOL.	SF-36 Modified Barthel Scale MOS short form McGill pain questionnaire EQ5-D
Haesler, 2015	Present evidence related to the reliability and validity of subjective assessments of lymphedema.	Not described	Literature review	PROMs can measure signs and symptoms associated with lymphedema.	FLQA-I GCLQ
Keast et al., 2019	Determine the prevalence and functional impact of chronic edema in adults at a national and international level.	68	Prevalence and impact of chronic edema	LEL is poorly recognized in comparison with UEL and is likely to become more prevalent. Early recognition and treatment are important to reduce morbidity and impact on function and QOL.	WHODAS 2.0 LYMQOL EQ-5D
Kim et al., 2017	Develop a shortened form of GCLQ.	67	Development study, not validated Retrospective cohort study	GCLQ-7 comprises 7 key questions from the original version of the GCLQ. Individual symptom clusters are represented, which may better distinguish patients with LEL.	GCLQ-7
Klernas et al., 2017	Investigate how people with lymphedema perceive its impact on their HRQOL and evaluate differences correlated to sociodemographic characteristics and various lymphedema locations and types.	200	Cross-sectional, multi-center study	HRQOL was not significantly affected in most people with lymphedema, a fifth of the participants was significantly impacted. People with LEL, younger people, and those who work were the most affected.	LyQLI SF-36 FACT-G
Lee et al., 2018	Explore the potential impact of lymphedema severity on QOL.	54	Cross-sectional study	Moderate-severe lymphedema pts still reported high QOL. DASH & LEFS scores found to be related to QOL, similar to previous studies.	DASH LEFS LYMQOL

Citation	Purpose	n	Study Type	Results	PROM Used
Lourduraj et al., 2020	Understand the feasibility and applicability of the LEFS among people with filarial lymphedema and to assess its correlation with the LEHRQOL.	60	Feasibility	LEFS is suitable to be used with people with LEL.	LEFS LEHRQOL
Ridner et al., 2018	Report on the further refinement and testing of the LSIDS-L.	388	Partial validation study	The LSIDS-L is internally consistent, consistent with reliability coefficients, and sensitive. It is valid and reliable to use with people with LEL.	Lymphedema Screening Questionnaire FAS-Q GCLQ Lymph-ICF-LL LSIDS-L
Viehoff et al., 2015	Describe the functioning and disability of people with lymphedema and identify the most common problems using the ICF to develop ICF Core Sets for lymphedema.	200	Cross-sectional study	All four components of ICF are relevant for people with lymphedema.	WHO-ICF
Weiss & Daniel, 2015	Investigate reliability and validity of LLIS	Test-retest reliability: 17 Internal consistency & validity: 102 Start & end of CDT: 62	Multi-center, cross-sectional study	LLIS is a valid and reliable tool to assess severity of impairment among people with lymphedema.	LYMQOL EORTC QLQ-C30 LLIS DASH LEFS
Weiss & Daniel, 2018	Assess the reliability and validity of the LLIS version 2.0	Test-retest reliability: 21 Construct, content, criterion validity; reliability: 84 MDC & MCID: 49	Validation study	LLIS version 2.0 is a comprehensive QOL PROM for lymphedema.	LLIS LYMQOL EORTC QLQ-C30 DASH LEFS
Yost et al., 2013	Develop and assess the accuracy of a screening questionnaire to detect LEL among obese and non-obese women.	99	Cross-sectional study	Screening identifies women with LEL based on self-reported signs and symptoms, has good predictive properties, and is sensitive and specific. Obesity is a risk factor for developing lymphedema, but it may mask the signs and symptoms of lymphedema	Screening questionnaire to detect LEL (unnamed)

PROMs

To assess general LE functioning in clients with lymphedema, the Functional Assessment Screening Questionnaire (FAS-Q) (Ridner et al., 2018), the Lower Extremity Function Scale (LEFS) (Carter et al., 2019; Lee et al., 2018; Lourduraj et al., 2020; Weiss & Daniel, 2015, 2018), the Modified Barthel Scale (Franks et al., 2006), and the World Health Organization International Classification of Functioning Disability and Health (WHO-ICF) (Cemal et al., 2013) were used. General pain was assessed with the MOS-Short Form McGill pain questionnaire (Cemal et al., 2013; Franks et al., 2006).

General signs and symptoms of LEL were assessed with the Lymphedema Screening Questionnaire (Ridner et al., 2018; Yost et al., 2013). The World Health Organization Disability Assessment Scale (WHODAS 2.0) was used to measure client-perceived levels of disability following their lymphedema diagnosis (Keast et al., 2019).

Many of the QOL measures used in research were general or focused on other or primary diagnoses versus those specific to lymphedema. The Medical Outcome Study-Short Form Health Survey Questionnaire (SF-36) (Cemal et al., 2013; Devooght et al., 2014; Franks et al., 2006; Klernas et al., 2017)

and Euroqol scale (EQ-5D) (Franks et al., 2006; Keast et al., 2019) were used as general QOL assessments. Oncology-specific QOL assessments included the European Organization for Research and Treatment of Cancer QOL Questionnaire core questionnaire version 3.0 (EORTC-QLQ-30) and the Functional Assessment of Cancer Therapy Scale-General (FACT-G) (Cemal et al., 2013; Klernas et al., 2017; Weiss & Daniel, 2015).

General lymphedema QOL assessments included the Freiburg Life Quality Assessment in Lymphedema (FLQA-I) (Haesler, 2015), the Lymphedema Quality of Life scale (LYMQOL) (Keast et al., 2019), the Lymphoedema QOL Inventory (LQOLI) (Klernas et al., 2017), the Lymphedema Health-related Quality of Life (LEHRQOL) (Lourduraj et al., 2020), and the Lymphedema Life Impact scale (LLIS) (Weiss & Daniel, 2015, 2018).

Cancer-related (CR) lymphedema QOL measures were the Instituto Dermopatico Dell'Immacolata-Italian Lymphedema Association part II (IDI-ILA part II) (Cemal et al., 2013), the Gynecologic Cancer Lymphedema Questionnaire (GCLQ) (Carter et al., 2019; Haesler, 2015; Ridner et al., 2018), and the Gynecologic Cancer Lymphedema Questionnaire short version (GCLQ-7) (Kim et al., 2017). Of the studies reviewed, only two described using QOL measures specific to LEL. LEL-specific QOL measures included the Lymphedema Functional, Disability, and Health Questionnaire for Lower Limb Lymphoedema (Lymph-ICF-LL) (Devooght et al., 2014) and the Lymphedema Symptom Intensity and Distress Survey-Lower Limb (LSIDS-L) (Ridner et al., 2018).

Literature Reviews

One systematic review evaluating PROMs in individuals with CR LEL (Cemal et al., 2013) and one literature review of subjective assessments of lymphedema in either UEs or LEs were found (Haesler, 2015). Cemal et al. (2013) evaluated six eligible articles for their systematic review and found a deficit in high-quality studies of QOL in persons with CR LEL. Haesler (2015) briefly reviewed 12 articles related to QOL in individuals with lymphedema, but only two of those studies included any discussion regarding LEL from any etiology. According to this study's findings of literature and previous reviews of the literature, there is a dearth of high-quality studies of QOL in people with CR LEL and an even greater deficit in the assessment and review of QOL and level of functioning in people with NCR LEL.

QOL Assessments in Lymphedema Research

Numerous studies have described the prevalence of lymphedema and how its presence in any part of the body impacts an individual's level of functioning, participation in preferred occupations, and QOL. Three studies used two lymphedema-specific QOL assessments, the LQOLI (Klernas et al., 2017) and the LYMQOL (Keast et al., 2019; Lee et al., 2018), to examine the impact of lymphedema on QOL. While lymphedema severity alone was not found to be significant in self-reported functional and QOL determinations, the location of lymphedema, the level of bio-impedance, the participant's age, the presence of wounds and/or other comorbidities, such as obesity, and post-surgery have more negative impacts.

Using a non-specific measurement, Viehoff et al. (2015) described the level of functioning and disability in individuals with lymphedema based on the International Classification of Functioning, Disability, and Health (ICF). Individuals reported broad functional deficits in all four aspects of the ICF (Activities and Participation, Body Functions, Body Structures, and Environmental Factors).

Further, Franks et al. (2006) examined the impact of LEL on QOL using various non-lymphedema-specific QOL tools. The study population included individuals with CR and NCR LEL and further

differentiated between people with and without current leg ulceration. No explicit lymphedema assessments were used (Franks et al., 2006).

Understanding the impact of LEL on QOL is critical to recognize the differences between the target outcomes of each of these studies. Studies focusing generally on lymphedema or a specific body part without a disease component allows for the comparison of the impact of lymphedema generally or with other disease conditions. However, this fails to assess how data specific to body parts better describes the impact of LEL on QOL. Multiple disease- and body part-specific PROMs of lymphedema have been developed in recent years. A closer examination of these studies is required to identify PROMs uniquely describing the QOL impact of LEL.

Development and/or Validation Studies. Eight articles described the more recent development and/or validation or translation/application of six general lymphedema or LEL specific PROMs: the LEFS (Lourduraj et al., 2020), GCLQ (Carter et al., 2019) and GCLQ-7 (Kim et al., 2017), LLIS (Weiss & Daniel, 2015, 2018), LSID-L (Ridner et al., 2018), Lymph-ICF-LL (Devooght et al., 2014), and the Lymphedema Screening Questionnaire (Yost et al., 2013).

Lower Extremity Functional Scale. The Lower Extremity Functional Scale (LEFS) was originally developed by Binkley to assess LE functional deficits in the presence of musculoskeletal problems (Mehta et al., 2016). Lourduraj and colleagues (2020) demonstrated a translated version of the LEFS, the Tamil version used in India, is suitable for evaluating LE functioning in individuals with lymphedema as with other disorders affecting the LEs. The English version has been used extensively in other studies of LE functioning in individuals with lymphedema (Carter et al., 2019; Lee et al., 2018; Weiss & Daniel, 2015). However, at the time of this writing the LEFS has not been validated in the LEL population.

Gynecological CR Lymphedema Questionnaires. The Gynecologic Cancer Lymphedema Questionnaire (GCLQ) and its short version (GCLQ-7) assess the QOL in individuals with gynecological CR lymphedema. The GCLQ effectively distinguishes between people who have had gynecological cancer with and without a later diagnosis of lymphedema. This measure was determined to have predictive value when combined with the assessment of limb volume change (LVC) (Carter et al., 2019). The short version (GCLQ-7) was developed later following the development and validation of a Korean version of the GCLQ (GCLQ-K), using a retrospective study of the data from the GCLQ-7; it was found to be reliable (Kim et al., 2017). It could not be determined if the GCLQ-7 has been translated into and validated in English. Both the GCLQ and GCLQ-7 assess physical functioning, general and limb-specific swelling, signs of infection, sensation, heaviness, and achiness (Carter et al., 2019; Kim et al., 2017). While both the GCLQ and GCLQ-7 assess LEL, they are diagnosis- and area-specific and may be used only with individuals who have CR LEL rather than any client with LEL, regardless of lymphedema etiology.

Limb Lymphedema Assessments. The Lymphedema Life Impact scale (LLIS) was originally developed and validated in 2015, and version 2.0 (LLIS version 2) was validated in 2018 (Weiss & Daniel, 2015, 2018). Both versions measure the impact of UE and LE lymphedema in physical, psychosocial, and functional domains. The LLIS includes questions regarding the incidence of infection and knowledge of lymphedema management, unlike other QOL scales, such as the LQOLI (Klernas et al., 2017), the Lymph-ICF-LL (Devooght et al., 2014), and the LYMQOL (Weiss & Daniel, 2018). Such questions are particularly important to assess and address as clients approach discharge from the clinical setting and self-manage their disease outside of the clinic (Weiss & Daniel, 2015, 2018). With 18 questions, and only five concerning a functional domain, the explicit level of functioning determinable by either version of

the LLIS is lacking. Further, the study was validated with significantly more white females than any other gender or race; therefore, QOL in other client populations should be further assessed.

LEL Measures. The Lymphedema Symptom Intensity and Distress Survey-Lower Limb (LSIDS-L) was developed and validated to measure LEL symptom presence and burden with regard to activity level, soft tissue and neurological sensation, pain, resource availability, psychosocial concerns, LE movement, and sexuality (Ridner et al., 2018). This study used individuals with CR and NCR lymphedema but did not specify what the NCR causes were, apart from differentiating between cases of primary and secondary lymphedema.

The Lymphoedema Functioning, Disability, and Health Questionnaire for Lower Limb Lymphedema (Lymph-ICF-LL) was developed and validated to assess physical and mental function, activity limitations, and participation in household tasks, mobility, and social life in individuals with LEL. It was originally developed and validated in Dutch and translated into English (Devoogdt et al., 2014). While the Lymph-ICF-LL includes more questions regarding explicit levels of function, no studies of its English version validation were found as of this writing (Devoogdt et al., 2014). Further, it does not appear individuals with NCR lymphedema were used to validate the study, apart from some clients with primary lymphedema.

The Lymphedema Screening Questionnaire was developed and validated to assist clinicians with detecting clinical lymphedema in the UEs and LEs (Yost et al., 2013). This screen was only validated using women with lymphedema and only includes questions regarding the physical signs and symptoms of lymphedema.

Discussion

While lymphedema may affect any area of the body, the LEs are the most commonly affected body part. LEL is more likely to have NCR causes, be bilateral, cause more infections, and more evenly affect both genders (Keast et al., 2019; Ridner et al., 2018; Wang & Keast, 2016). While literature acknowledges the many areas of participation in social and functional areas impacted by LEL, this review's findings show assessing a client's perceptions of improvements in this area fails to capture disease- and location-specific barriers to achieving a high QOL or satisfaction with and participation in meaningful occupations.

While the severity of lymphedema does not necessarily correlate to patient-reported QOL, the level of functioning and increased number of comorbidities, including pain and skin tightness and changes, such as infection and ulcerations, and limb heaviness does (Franks et al., 2006; Lee et al., 2018; Weiss & Daniel, 2015, 2018). For example, when people with LEL are able to participate in their preferred occupations, they continue to report high QOL, even if they have moderate to severe lymphedema (Franks et al., 2006). Poorer scores on functional assessments, such as the LEFS, are better indicators of poorer QOL (Lourduraj et al., 2020). While non-lymphedema-specific, functional tests have been indicated for use in clinical practice to assess the impact of the condition on LE function reliably (Mehta et al., 2016), occupation-based assessments focusing on client-preferred occupations have not been used to study lymphedema explicitly. The lack of research that incorporates occupation-based assessments is troubling, given that higher participation levels link to higher QOL independent of the severity of lymphedema.

Limitations

For this scoping review, only 15 articles were found that met all inclusion criteria from PubMed and CINAHL. Other databases or a review of the grey literature may have yielded more results. The total number of articles found is low, despite the prevalence of LEL from both cancer- and noncancer-related etiologies. Articles found were heavily focused on CR LEL. As English-only articles were explored, other

studies may exist in non-English literature. Further, most studies of QOL in patients with LEL primarily used generic QOL PROMs, although numerous lymphedema- and LEL-specific QOL PROMs were also identified. No standard QOL PROM was identified to measure QOL in those with LEL.

Future Research

Despite its greater prevalence and impact on QOL and functioning, LEL remains poorly studied, especially from NCR etiologies and more equally across all genders and ethnicities. Based on this review's findings, QOL studies more frequently used general QOL assessments rather than disease- and/or disease- and body part-specific measurement tools (Keast et al., 2019; Klernas et al., 2017; Viehoff et al., 2015). Lymphedema- and LEL-specific assessments of QOL exist and should be used more in the research on the condition and its impact on functioning and QOL to help medical providers better understand the disease's effect on satisfaction with and participation in meaningful occupation (Carter et al., 2019; Devooght et al., 2014; Kim et al., 2017; Lourduraj et al., 2020; Ridner et al., 2018; Weiss & Daniel, 2015, 2018; Yost et al., 2013). Despite occupational therapists working with this client group, there is little to no professional literature describing approaches for assessment approaches for NCR LEL. As a profession with increasing numbers of CLTs and referrals of clients with LEL, occupational therapy is well positioned to identify its distinct value in working with clients with LEL with research using occupation-based assessments. From this scoping review, areas for new research are identified that specifically call out the use of QOL targeted for LEL and satisfaction with functional participation in prioritized activities of daily living. These recommendations include:

- A systematic review of available NCR LEL QOL assessments.
- A systematic review of the impact of NCR LEL on QOL and/or participation in and satisfaction with meaningful occupations.
- A phenomenological study of how lymphedema impacts participation in meaningful occupation.
- A QOL study further using and/or validating already existing disease and/or body part specific measurement tools in diverse populations.
- Research including more occupation-based measures along with QOL assessments.

Conclusion

The purpose of this scoping review was to identify and compare PROMs of QOL and/or level of functioning in individuals with LEL and summarize this material to inform occupational therapists working with clients with NCR LEL. Some disease and body part specific assessments exist, but their use in research has been limited apart from their initial development and validation studies from the original authors. LEL remains poorly studied, especially when caused by NCR etiologies, such as chronic venous insufficiency, obesity, and trauma-related obstruction, and in diverse client populations. Acknowledging clients with LEL have unique concerns demands having research that accurately assesses outcomes specific to LEL. These studies could further provide information regarding the impact of LEL on daily function and QOL, as well as intervention effectiveness. The profession of occupational therapy is well-positioned to lead research with this client population using a combination of limb-specific functional measures and occupation-based assessments in efforts to improve overall QOL for clients with LEL.

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