

Function and Quality of Life of Individuals With Lower Extremity Lymphedema: A Scoping Review

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PURPOSE: Lymphedema—chronic swelling present for 3 months or more—in the lower extremities (LEs) is more prevalent than in other body parts but is less frequently studied, especially in comparison with the upper extremities (UEs). Direct transfer of information from lymphedema in the UEs to LEs is inappropriate because of the differences in size, volume, location, skin changes, and function between the UEs and LEs. Both UEL and LEL, impair ability to complete activities of daily living (ADLs), increase employment difficulties, and prohibit participation in preferred leisure activities. LEL further causes gait dysfunction, marital and sexual problems, and mobility deficits. Assessing the impact of LEL on occupational functioning and quality of life (QOL) is essential to client-centered care in occupational therapy (OT). Patient-reported outcome measures (PROMs) provide increased insight into a person's perceptions regarding a variety of topics including QOL. Current understanding of how and which PROMs are used with clients with LEL to identify the impact of intervention effectiveness is under-reported in the literature. The purpose of this study was to identify and compare the patient-reported outcome measures available to assess QOL and/or level of functioning in individuals with lower extremity lymphedema (LEL) and studies using such assessments.

DESIGN: A scoping review was completed. Articles were excluded if they were not published in English, described PROMs used to assess QOL or function only in participants with non-LEL, primary study population was children, or represented symptom and/or diagnostic subjective or objective assessments. Further, articles in abstract or poster presentation form were also excluded. English language, full text articles identifying or using PROMs of LEL to measure QOL or level of functioning were identified. Inclusion criteria included: 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 level of functioning, participation in preferred occupations, and QOL; and results describing other assessments to measure disability, QOL, and function.

METHOD: A review of literature published in PubMed and CINAHL Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases from January 1990 through December 2019 was performed. In total, 494 articles were originally located, and 17 met inclusion criteria: 1 systematic review, 1 literature review, 7 studies of QOL in patients with lymphedema, and 8 description and/or validation studies of QOL PROMs.

RESULTS: Disease- and body part-specific assessment PROMs were identified in development and/or validation studies. However, general QOL and functional PROMs rather than disease-specific measures were used more frequently in impact studies of LEL.

CONCLUSION: LEL remains poorly studied. Further work is needed to use disease-specific QOL and functional evaluation tools in assessment of lymphedema's impact on people with the condition. 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 OT field 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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