

WHAM Evidence summary: Lymphoedema: Subjective assessment

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CLINICAL QUESTIONS

What is the best available evidence on the reliability and validity of self-reported signs and symptoms of lymphoedema?

KEYWORDS

Lymphoedema, oedema, lymphatic system, assessment

SUMMARY

There is a large selection of tools and questionnaires that are used in assessment of self-reported symptoms.¹⁻⁵ The most common patient-reported signs and symptoms of lymphoedema are limb heaviness, swelling, redness, tenderness, change in sensory perception and inability to fit clothing.⁶ These patient-reported signs and symptoms have also been shown to be reliable indicators of objective measures of limb size^{1, 6, 7} (*Level 2 and 5*).

CLINICAL PRACTICE RECOMMENDATIONS

All recommendations should be applied with consideration to the wound, the person, the health professional and the clinical context:

A self-report assessment tool could be used to measure signs and symptoms associated with lymphoedema (Grade B).

SOURCES OF EVIDENCE

This summary was conducted using methods published by the Joanna Briggs Institute.⁸⁻¹¹ This evidence summary is based on a structured database search using variations of the search terms describing lymphoedema and assessment. Searches were conducted in EMBASE, Medline, AMED and the Cochrane Library for evidence from 1990 to October 2014 in English. Levels of evidence for diagnostic studies are reported in the table below.

BACKGROUND

Lymphoedema is a form of chronic, progressive oedema in which there is significant, persistent swelling of a limb or other body region due to excess and abnormal accumulation of protein-rich fluid in body tissues. The lymphatic system is unable to manage the volume of accumulated fluid.¹²

Table 1: Sources of clinical evidence and the level

Level 1 Evidence	Level 2 Evidence	Level 3 Evidence	Level 4 Evidence	Level 5 Evidence
Studies of test accuracy among consecutive patients	Studies of test accuracy among non-consecutive patients	Diagnostic case control studies	Diagnostic yield studies	Expert Opinion/ Bench Research
1.b Study of test accuracy among consecutive patients ³	2.a Systematic review of studies of test accuracy among non-consecutive patients ⁶ 2.b Study of test accuracy among non-consecutive patients ^{5, 7}	3.b Diagnostic case-control study ¹	4.2 Systematic review of diagnostic yield studies. ⁴ 4.b Individual diagnostic yield study ^{13, 14}	5.c Expert opinion ^{12, 15}

Lymphoedema occurs due to primary, secondary or mixed causes. Primary causes are described as congenital (e.g. an inherited disorder such as Milroy's disease), praecox (onset at puberty, e.g. Meige's disease) or tarda (sudden onset no apparent cause).¹⁶⁻¹⁸ Secondary causes arise from direct damage or trauma to the lymphatic system such as injury surgery or radiotherapy (usually related to treatment of breast cancer), or parasitic invasion.^{16, 17, 19} Lymphatic filariasis (also called elephantitis) is a cause of secondary lymphoedema endemic in areas primarily in Africa and Asia. Lymphatic filariasis is a parasitic (roundworm) infection that is spread by mosquitoes and causes damage to the lymphatic system that may result in lymphoedema. Infection generally occurs in childhood, although. Management focuses on large-scale treatment programs to reduce disease spread.²⁰ Mixed lymphoedema describes lymphoedema arising from decompensation or failure of the lymphatic system associated with other disease or conditions, including but not limited to obesity, immobility, venous disease or lipoedema.^{16, 17, 21}

Without management, lymphoedema may lead to:^{12, 22}

- progressive swelling,
- physical and functional limitations,
- chronic infection,
- fibrosis,
- lymphorrhoea (leaking of lymph fluid)
- pain and discomfort, and
- reduced ability to undertake activities of daily living (ADLs).

Intermittent pneumatic compression produces a pressure gradient through sequential inflation and deflation that is thought to promote the relocation of accumulated fluid from interstitial space into the lymphatic system, thereby reducing oedema.^{23, 24} However, some studies suggest that protein may not shift with fluid, reducing the long term sustainability of the intervention.²⁵

Comprehensive assessment of lymphoedema includes objective measures of volume/size, and subjective assessment of signs and symptoms, including their impact on the patient.¹ In patients with mixed lymphoedema, it is also important to assess factors associated with the underlying disease or condition (not addressed in this evidence summary).

This evidence summary presents evidence related to the reliability and validity of one objective measurement used to assess lymphoedema: circumference measurement.

Circumference measurement involves measuring around the oedematous limb using a measurement tape.¹² Circumference measurement, which is the most commonly used strategy for diagnosis and assessment of lymphoedema,²⁶ is reported to be both the easiest and most cost-effective strategy to assess limb size.^{6, 27}

CLINICAL EVIDENCE

Self-reported symptoms compared to objective measurements

A systematic review included eight studies that reported on the use of a visual analogue scale (VAS) to measure various signs and symptoms of lymphoedema. The review reported that a 10-point VAS measuring swelling is moderately correlated with objective measures of swelling via limb circumferences, perometry and bioimpedance spectroscopy⁶ (Level 2).

One cohort study (n=51) compared the reliability of self-reported "current swelling" with circumference measure with results used to calculate a volume, perometry and bioimpedance spectroscopy. Subjective assessment of swelling was rated immediately prior to objective measurements using a 10cm visual analogue scale (VAS). Reliability of self-report was moderate (intraclass coefficient [ICC] = 0.50, 95% confidence interval [CI] 0.20 to 0.72). There was a moderate correlation between self-report and perometry ($r = 0.65$, $p < 0.001$), moderate correlation with circumference measurement used to calculate volume ($r=0.66$, $p < 0.001$) and high correlation with bioimpedance spectroscopy ($r = 0.71$, $p < 0.001$)⁷ (Level 2).

One study conducted in a cohort women following breast cancer treatment (n = 40) and a comparison group of healthy women (n = 40) found that two self-reported symptoms "heaviness experienced in the past year" (odds ratio [OR] = 7.995, 95% CI 1.168 to 54.726, $p = 0.0279$) and "current swelling" (OR = 96.889, 95% CI 9.865 to 951.611, $p = 0.0007$) were significant predictors of a limb difference of 2 cm or more. The symptom "numbness in the past year" was found to be unrelated to an objective difference in limb size. The findings were tested and confirmed in a second study that included 103 women who

had undergone breast cancer surgery and/or radiation¹ (*Level 3*).

One validation study conducted in a cohort women following breast cancer treatment (n=617) found poor correlations between the total score on the Morbidity Screening Tool (MST) and limb measurement using perometry for all participants (n = 429, rho = 0.18, p = 0.043) and for women who were more than 12 months post treatment (n = 377, rho = 0.19, p < 0.001). The MST score was not significantly related to perometry in women who were less than 12 months post treatment (n = 49, rho = 0.15, p = 0.326)¹³ (*Level 4*).

Tools and questionnaires for assessing subjective experience of lymphoedema

A range of tools and questionnaires are available for assessing signs and symptoms of lymphoedema. These tools generally include either a VAS or Likert scoring by which the patient self-rates the presence, severity and, on some scales, the importance or impact of the sign or symptom on their life.

The data indicates that there is a large selection of tools and questionnaires that are valid and reliable in assessment of self-reported. The tools generally include similar physical symptoms, but the range of activities that the patient is asked to rate in terms of functional limitation differs (e.g. some tools focus heavily on domestic tasks, others include sport, driving and impact in the work place). Selection of a tool may be made based on the patient's profile (e.g. the type of activities he or she normally undertakes), ability to complete a self-report scale and tool availability. Psychometric data on most commonly reported tools and questionnaires is reported below.

A systematic review of six studies reported that the Disability of the Arm, Shoulder and Hand questionnaire (DASH) has demonstrated validity and excellent intrarater reliability (ICC=0.92 to 0.96). In breast cancer patients, a change of at least 10.2 on the DASH questionnaire indicates a clinically significant difference.⁴ (*Level 4*).

A systematic review of two studies reported that the Functional Assessment of Cancer Therapy – Breast questionnaire (FACT-B) has good internal consistency ($\alpha = 0.88$), good intrarater reliability for arm morbidity scales (r = 0.79 to 0.95) and is sensitive to change over time⁴ (*Level 4*).

A systematic review of three studies reported that the Upper Limb Lymphoedema Measure (ULL-27) has

demonstrated internal consistency ($\alpha = 0.82$ to 0.93), good intrarater reliability (ICC = 0.70 to 0.86) and is sensitive to change over time⁴ (*Level 4*).

One study conducted in a cohort women following breast cancer treatment (n=40) and a comparison group of healthy women (n=40) found that the LBCQ had good internal consistency (r=0.785) and excellent interrater reliability (r=0.98)¹ (*Level 3*).

One validation study reported that the Gynaecologic Cancer Lymphoedema Questionnaire (GCLQ) for self-reported assessment had strong internal consistency (area under curve [AUC]=0.95) when used with patients who had lower limb oedema (n=28) and a cohort with no oedema (n=30). The tool was found to have perfect specificity (100%) and moderate sensitivity (64%) when a cut-off score of at least 6 was used to diagnose lymphoedema.³ (*Level 1*).

One validation study conducted in women with (n = 30) and without (n = 30) lymphoedema following breast cancer surgery reported that the Lymphoedema Functioning, Disability and Health Questionnaire (Lymph-ICF) has strong internal consistency ($\alpha = 0.92$), excellent intrarater reliability (ICC = 0.93, 95% CI 0.89 to 0.96) and is sensitive to change over time⁵ (*Level 2*).

One validation study conducted in a cohort women following breast cancer treatment (n = 617) found a significant correlation between the MST score and scores on the LBCQ, the DASH, the Chronic Pain Grade Questionnaire (CPGQ), and the FACT-B.¹³ (*Level 4*).

One validation study (n = 177 male and female inpatients with primary and secondary lymphoedema) reported that the Freiburg Life Quality Assessment in Lymphoedema (FLQA-I) has strong internal consistency ($\alpha = 0.85$ to 0.94) and moderate to excellent interrater reliability (r = 0.59 to 0.87). There was good correlation (r = 0.66 to 0.77) between FLQA-I and two generic quality of life scales (ALLTAG and Nottingham Health Profile). The FLQA-I showed sensitivity to change following four weeks of specific therapy for lymphoedema, with significant changes (p < 0.001) on six of seven scales, including a physical complaints scale¹³ (*Level 4*).

Table 2: Symptoms included on valid and reliable self-assessment tools

	Gynecologic Cancer Lymphoedema Questionnaire (GCLQ) ³	Freiburg Life Quality Assessment in Lymphoedema (FLQA-1) ²	Disability of the Arm, Shoulder and Hand questionnaire (DASH)	Lymphoedema and Breast Cancer Questionnaire (LBCQ) ¹³	Lymphoedema Functioning, Disability, and Health Questionnaire (Lymph-ICF) ^{4, 5}	Morbidity Screening Tool - Lymphoedema ¹³	Functional Assessment of Cancer Treatment – Breast (FACT-B) ⁴	Upper Limb Lymphoedema Measure (ULL-27) ⁴
lower/upper extremity	lower	lower /upper	upper	upper	upper	upper	upper	upper
estimated completion time		not reported	5-7 mins	not reported	5 mins	not reported	not reported	11 mins
number of items	24	?	30	?	29		36	27
tiredness						X		
functional ability			X		X	X	X	X
difficulty moving	X				X	X		X
current swelling	X			X	X	X	X	X
tenderness	X						X	
tingling			X		X			X
weakness			X		X			
stiffness			X		X			
heaviness	X			X	X	X		X
numbness	X			X				X
current aches or pain	X		X		X	X		
itch						X		
scaly/dry skin						X		X
blistering	X							
firmness/tightness	X				X			
skin pitting	X							X
skin temperature	X					X		
sleep			X		X			
social well being			X		X		X	
body image								X

CONFLICTS OF INTEREST

The author declares no conflicts of interest in accordance with International Committee of Medical Journal Editors (ICMJE) standards.

FUNDING

The author would like to acknowledge the support of the Australian Government's Cooperative Research Centres Program.

ACKNOWLEDGEMENT

Members of the Australasian Lymphology Association for their assistance with peer review.

ABOUT WHAM EVIDENCE SUMMARIES

WHAM evidence summaries are consistent with methodology published in

Munn Z, Lockwood C, Moola S. The development and use of evidence summaries for point of care information systems: A streamlined rapid review approach, *Worldviews Evid Based Nurs*. 2015;12(3):131-8.

Methods are provided in detail in resources published by the Joanna Briggs Institute as cited in this evidence summary. WHAM evidence summaries undergo peer-review by an international review panel. More information is available on the WHAM website: <https://www.whamwounds.com/>.

WHAM evidence summaries provide a summary of the best available evidence on specific topics and make suggestions that can be used to inform clinical practice. Evidence contained within this summary should be evaluated by appropriately trained professionals with expertise in wound prevention and management, and the evidence should be considered in the context of the individual, the professional, the clinical setting and other relevant clinical information.

PUBLICATION

This evidence summary has been published in *Wound Practice and Research*:

Haesler E. Evidence summary: Lymphoedema: Subjective assessment. *Wound Practice and Research*, 2015; 23(1): 33-5.

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