

# Evidence Summary: Lymphoedema: Subjective Assessment

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## QUESTION

What tools are available to assess signs and symptoms of lymphoedema?

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

## SUMMARY

The data<sup>1-5</sup> indicate that there is a large selection of tools and questionnaires that are valid and reliable in assessment of self-reported symptoms (Level 1.b evidence). 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.<sup>6</sup> These patient-reported signs and symptoms have also been shown to be reliable indicators of objective measures of change in limb size<sup>1, 6, 7</sup> (Level 1.b evidence).

## BACKGROUND

Lymphoedema is a form of chronic, progressive edema 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.<sup>8-12</sup> The lymphatic system is unable to manage the volume of accumulated fluid.<sup>11</sup>

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. Meigs' disease) or tarda (sudden onset no apparent cause).<sup>13-15</sup> 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.<sup>14-16</sup> Lymphatic filariasis (also called elephantitis) is a cause of secondary lymphoedema in endemic areas primarily in Africa and Asia. Lymphatic filariasis 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. Management focuses on large-scale treatment programs to reduce disease spread.<sup>12, 17</sup> 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 lipodema.<sup>14, 15, 18</sup>

Without management, lymphoedema may lead to:<sup>11, 19</sup>

- progressive swelling,
- physical and functional limitations,
- chronic infection,
- fibrosis,
- lymphorrhoea (leaking of lymph fluid), and
- pain and discomfort.

Comprehensive assessment of lymphoedema includes objective measures of volume/size, and subjective assessment of signs and symptoms, including their impact on the patient.<sup>1</sup> 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 subjective strategies used to assess lymphoedema.

## CLINICAL BOTTOM LINE

### *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 spectroscopy.<sup>6</sup> (Level 1.b evidence). However the authors concluded that they were unable to recommend the use of this tool due to limited evidence being available.
- 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 ( $r=0.71$ ,  $p<0.001$ ).<sup>7</sup> (Level 3.c evidence)

- 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 radiation.<sup>1</sup> (Level 3.c evidence)
- One validation study conducted in a cohort women following breast cancer treatment ( $n=617$ ) found a 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 ( $n=49$ ,  $\rho=0.15$ ,  $p=0.326$ ).<sup>20</sup> (Level 4.b evidence)

#### 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<sup>1-5</sup> indicate that there is a large selection of tools and questionnaires that are valid and reliable in assessment of self-reported symptoms (Level 1.b evidence). 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.

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Symptoms included on valid and reliable self-assessment tools

	Gynecologic Cancer Lymphedema Questionnaire (GCLQ) <sup>3</sup>	Freiburg Life Quality Assessment in Lymphedema (FLQA-1) <sup>2</sup>	Disability of the Arm, Shoulder and Hand questionnaire (DASH)	Lymphedema and Breast Cancer Questionnaire (LBCQ) <sup>20</sup>	Lymphoedema Functioning, Disability, and Health Questionnaire (Lymph-ICF) <sup>4, 5</sup>	Morbidity Screening Tool- Lymphoedema <sup>20</sup>	Functional Assessment of Cancer Treatment – Breast (FACT-B) <sup>4</sup>	Upper Limb Lymphoedema Measure (ULL-27) <sup>4</sup>
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

- 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.<sup>4</sup> (Level 1.b evidence)
- 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 time.<sup>4</sup> (Level 1.b evidence)
- 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 time.<sup>4</sup> (Level 1.b evidence)
- 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 ( $r=0.98$ ).<sup>1</sup> (Level 3.c evidence)

- 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 edema (n=28) and a cohort with no edema (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.<sup>3</sup> (Level 3.c evidence)
- 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 time.<sup>5</sup> (Level 3.c evidence)
- One validation study conducted in a cohort of 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.<sup>20</sup> (Level 4.b evidence)
- One validation study (n=177 male and female inpatients with primary and secondary lymphoedema) reported that the Freiburg Life Quality Assessment in Lymphedema (FLQA-I) has strong internal consistency ( $\alpha=0.85$  to  $\alpha=0.94$ ) 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 scale.<sup>2</sup> (Level 3.e evidence)

## CHARACTERISTICS OF THE EVIDENCE

This evidence summary is based on a structured literature and database search combining search terms that describe lymphoedema and assessment. Additional searches were conducted on specific tools used for subjective assessment of lymphoedema. The evidence in this summary comes from:

- Systematic reviews of studies of various design<sup>4, 6, 9</sup> (Level 1.b evidence)
- Cohort studies with control groups<sup>3, 5, 7, 8</sup> (Level 3.c evidence)
- Cohort studies with no control group<sup>1, 2, 16</sup> (Level 3.e evidence)
- A retrospective cross-sectional study<sup>20</sup> (Level 4.b evidence)
- Case series report<sup>18</sup> (Level 4.c evidence)
- Expert consensus<sup>12, 14</sup> (Level 5.b evidence)
- Single expert opinion<sup>10, 11, 13, 15, 17, 19</sup> (Level 5.c evidence)

## BEST PRACTICE RECOMMENDATIONS

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

### Related topics

JBI Evidence Summary 10912 Identification of people at risk of venous leg ulcers

## ACKNOWLEDGEMENTS

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