

MANUAL LYMPH-ICF-UL QUESTIONNAIRE FOR UPPER LIMB LYMPHOEDEMA

Introduction

Lymph-ICF-UL questionnaire = Lymphoedema Functioning Disability and health questionnaire for upper limb lymphoedema.

In 2011 the Lymph-ICF questionnaire for upper limb lymphoedema has been developed. The original language is Dutch. Each question in the questionnaire has to be scores on a Visual Analogue Scale (0-100).(1)

In 2014 the Lymph-ICF-LL questionnaire for lower limb lymphoedema has been developed. The original language is also Dutch. Since subjects indicated that they preferred a scoring system with gradation, a Numeric Rating Scale (0-10) was used.(2)

In 2016, in agreement with the Lymph-ICF-LL questionnaire, the Lymph-ICF was revised: Visual Analogue Scale was replaced in Numeric Rating Scale (0-10) and the name of the questionnaire was changed in Lymph-ICF-UL.(3) Also responsiveness of this questionnaire has been investigated.(4)

Purpose of the Lymph-ICF-UL questionnaire

The purpose of the Lymph-ICF-UL questionnaire is to assess problems in functioning (i.e. impairments in function and activity limitations and participation restrictions) of patients with breast cancer-related arm lymphoedema. It is a descriptive and evaluative tool.

Description of Lymph-ICF-UL questionnaire

The Lymph-ICF-UL consists of 29 questions.

The questionnaire consists of 5 domains: physical function domain contains 7 questions; mental function domain contains 4 questions; household domain contains 4 questions; mobility domain contains 8 questions; and the life/ social life domain contains 6 questions.

Each question has to be scored on an 11-point scale (0 to 10). The anchor points for the physical and mental function domain, and household domain are 'not at all' and 'a lot'. Those for the mobility and life domain/ social life domain were 'very well' and 'not at all'.

The patient has to score his/ her **average problems in functioning** (i.e. impairments in function and activity limitations and participation restrictions) due to the upper limb lymphoedema **of the previous 2 weeks**.

Furthermore, the patient may not to discuss the questions with anyone to maintain the **self-assessment** characteristic of the questionnaire.

The Lymph-ICF-UL takes 5 minutes to complete.

Processing of Lymph-ICF-UL questionnaire

Each of the 29 questions account for a score between 0 and 10.

For calculation of the scores: see table below.

Total score (0-100)	<u>Som of scores on all questions</u> 29 – number of questions not answered X 10
Fysieke functie score (0-100)	<u>Som of scores on all questions</u> 7 – number of questions not answered X 10
Mentale functie score (0-100)	<u>Som of scores on all questions</u> 4 – number of questions not answered X 10
Huishouden score (0-100)	<u>Som of scores on all questions</u> 4 – number of questions not answered X 10
Mobiliteit score (0-100)	<u>Som of scores on all questions</u> 8 – number of questions not answered X 10
Belangrijke levensgebieden/ sociaal leven score (0-100)	<u>Som of scores on all questions</u> 6 – number of questions not answered X 10

Moreover, the excel-file in attachment may be used for calculation of the scores.

Interpretation of Lymph-ICF-UL questionnaire

As recommended by the WHO taxonomy, the interpretation of the score occurred as follows:

A score:

- between 0 and 4 = 'no problem'
- between 5 and 24 = 'a small problem'
- between 25 and 49 = 'a moderate problem'
- between 50 and 95 = 'a severe problem'
- between 96 and 100 = 'a very severe problem'.

Measuring properties of Lymph-ICF questionnaire (with VAS)

Published in Physical Therapy: Devoogdt et al 2011(1) and in Lymphatic Research and Biology: De Vrieze et al 2019(3)

Reliability

Test-retest reliability: Intraclass Correlation Coefficients for the total score and domain scores ranged between 0.65 and 0.93 for Lymph-ICF with VAS and between 0.79 and 0.95 for Lymph-ICF with NRS.

Internal consistency: Cronbach's alpha coefficients for the domain scores were more than 0.70.

Measurement variability: There were no systematic changes from the first to the second test occasion and measurement variability was acceptable (For Lymph-ICF with VAS: SEM ranged between 4.8 and 12.5; for Lymph-ICF with NRS: SEM ranged between 4.9 and 12.3).

Validity

Content validity: was good because:

- For Lymph-ICF with VAS: all questions were understandable for all patients, scoring system (VAS-scale) was clear for 88% of the patients and all complaints due to their arm lymphoedema were mentioned for 85% of the patients.
- For Lymph-ICF with NRS: all questions were understandable for all patients, scoring system (VAS-scale) was clear for all patients and all complaints due to their arm lymphoedema were mentioned for 98% of the patients.

Construct validity: was good.

- Convergent validity was good:
 - o For Lymph-ICF with VAS: 5 expected domains of the Lymph-ICF had the strongest correlation with 5 expected domains of the SF-36. So, the 5 (of 5) hypotheses assessing convergent validity were accepted.
 - o For Lymph-ICF with NRS: 4 (of 5) hypotheses assessing convergent validity were accepted.
- Divergent validity was good:
 - o For Lymph-ICF with VAS: 3 of 5 hypotheses assessing divergent validity were accepted.
 - o For Lymph-ICF with NRS: 7 (of 9) hypotheses assessing divergent validity were accepted.
- Known groups validity was good:
 - o For Lymph-ICF with VAS: patients with lymphoedema had a higher total score on the Lymph-ICF and had a higher score on each domain and on each question (except one) than patients without lymphoedema.
 - o For Lymph-ICF with NRS: not investigated

Responsiveness

Lymph-ICF-UL (Lymph-ICF with NRS) is responsive to change after decongestive lymphatic therapy:

- The Lymph-ICF-UL total score changed significantly in the intensive group ($p < 0.001$) and non-significantly for those in the stable group ($p = 0.25$).
- The Standardised Response Mean (SRM) represented moderate responsiveness (0.65)
- Patients who reported a clinical improvement (= responders) after intensive treatment showed a significant decrease in total score ($p < 0.001$), this was also the case for non-responders ($p < 0.001$). There was a significant difference in mean total score changes between responders and non-responders ($p < 0.001$).
- Minimal Clinical Important Difference (MCID) for the total score was 9%.

Languages

Reliability and validity of Lymph-ICF-UL of translations into other languages was also investigated and found to be good:

Dutch (VAS, NRS) (1, 3)

Chinese (NRS) (5)

French (NRS) (6)

Danish (7)

Turkish (8)

Lymph-ICF-UL has also been translated in other languages, such as English (with NRS score), Thai (with NRS score), Greece (with VAS score) and Italian (with VAS score).

References

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