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LYMPHEDEMA QUALITY OF LIFE INVENTORY (LyQLI)-Development and investigation of validity and reliability

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Abstract

Purpose The purpose of this study was to reduce the 188-item Swedish Lymphedema Quality of Life Inventory (SLQOLI) to an abbreviated, clinically useful version (phase 1) and to test it for reliability and validity (phase 2).

Methods In phase 1 correlation analysis, factor analysis, content validity assessment and expert panels were used to reduce the number of items in SLQOLI to 45 items, which was named, Lymphedema Quality of Life Inventory (LyQLI). In phase 2 LyQLI was sent to 200 patients with lymphedema. One hundred twenty-six patients completed the questionnaire twice to determine stability of the instrument over time. SF-36 was sent to the patients once, correlations between the three domains in LyQLI and the two sum scores Physical Health (PCS) and Mental Health (MCS) in SF-36 were used to assess concurrent validity.

Results The 188-item SLQOLI was reduced to 45-item LyQLI. Four domains were reduced to three; physical, psychosocial and practical. Reliability estimates using ICC for the physical and psychosocial domain were 0.88 ($p < 0.01$) and 0.87 ($p < 0.01$), for the practical domain 0.87 ($p < 0.01$). Cronbach's alpha coefficients for the three domains were 0.88, 0.92, and 0.88, respectively. The physical domain correlated highly significantly with PCS, psychosocial highly significantly with MCS, and practical equally highly significantly to both PCS and MCS. Using skewness coefficients small floor effects in the items were found.

Conclusion The shorter LyQLI demonstrated good reliability and validity with potential use to assess quality of life in clinic settings and in further cross-sectional studies of patients with lymphedema.

Keywords

Health-Related Quality of Life, lymphedema, disease-specific instrument, Reliability, Validity

Introduction

Lymphedema (LE) is defined as swelling of one or more parts of the body because of impairments in lymph transport capacity based on malfunction or malformation of the lymphatic system. Without adequate treatment LE can result in complications such as massive edema, lymphangitis/cellulitis, impaired limb function, psychosocial disability, and even malignant complications [1-4]. LE is most often a chronic condition which requires lifelong treatment including conservative treatment such as daily wrapping with non-elastic bandages and/or compressive garments, manual lymphatic drainage, intermittent pneumatic [2-5] and in some cases surgical treatment [6] or lymphatic venous anastomosis [7].

LE can be classified as primary or secondary LE. The etiology of primary LE is not well known; however, in children nearly all LE is classified as primary [1]. Secondary LE is much more frequent [3]. It can result from obstruction or disruption of the lymphatic system, which can occur as a consequence of malignancy, surgery, radiation therapy, trauma, inflammation or infections such as filariasis. The resulting mechanical insufficiency can lead to accumulation of fluid in the interstitial tissues [8]. In Western societies, the most common cause of secondary LE is cancer treatment [3]. LE has been described as one of the most significant survivorship impairments after the surgical treatment of breast cancer. Apart from breast cancer, secondary LE also has been reported as a consequence of treatment for several solid tumors, including melanoma, head and neck, gynecological and genitourinary malignancies and sarcomas [8].

Traditionally LE has been viewed as a relatively unimportant complication of essential life-saving treatment for cancer. However, recently it has been shown that it can cause physical symptoms such as pain and discomfort, impaired physical and social functions and emotional effects and is now recognized as a complex problem that can strongly influence patients Health-Related Quality of Life. Patients with LE may experience depression and some report that coping with LE is more distressing than coping with the cancer itself [9]. Therefore, LE may have severe consequences in the terms of the patient's functional, mental, practical and social aspects of life [9-11].

This paper uses the concepts health, Quality of life and Health-Related Quality of Life (HRQL) to explore the problems that patients with LE encounter. The World Health Organization (WHO) definition of Health was signed in 1946 and in 1993 WHO put forward a definition of quality of life linked to health "The perception by individuals of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [12].To distinguish between quality of life in its more general sense and the requirements of clinical medicine and clinical trials the term HRQL is used [13]. HRQL can be defined in many different ways, but in 1992 an international Board of Advisors in south Caroline stated a consensus that four fundamental dimensions including physical, mental/psychological, and social health, as well as global perceptions of function and well-being were essential to any HRQL instrument. They also stated study participants to be the primary source in any HRQL investigation, if possible [14].

A number of questionnaires have been used to asses HRQL in patients with LE, with most instruments being either generic or cancer-specific. Several researchers have focused on HRQL in patients after breast cancer treatment. They have used cancer-specific instruments such as "EORTC QLQ-BR23" [15] and "Functional Living Index-Cancer" [16], or generic instruments such as Medical Outcome Study-36 item short form (SF-36) [17-19] and the "Nottingham Health Profile Part 1" (NHP-1) [20-21]. The researchers found that breast cancer patients with LE were more disabled, experienced poorer HRQL and had increased psychological distress compared to survivors without LE [22-25] but they also often found that these instruments were not sensitive enough [26]. A few studies had examined HRQL in patients with non-cancer-related LE. Bogan et al. used a qualitative approach and found that people with non-cancer-related LE in lower limbs score their HRQL as low [4]. Studies with quantitative approaches often used generic instruments with similar results, but they also concluded that the lack of disease-specific approach is a problem [9, 27].

In recent years there has been more interest in developing LE-specific HRQL tools. The "Upper limb lymphedema 27" (ULL-27) is specially designed and validated for assessing HRQL in patients with upper-limb LE [28]. The "Lymphedema functioning, disability and health questionnaire" (Lymph-ICF) also focuses on upper-limb LE. It was tested for reliability and validity in Belgium [29]. Augustin et al. developed and validated a disease-specific HRQL questionnaire for patients with LE in lower-limbs (FLQA-I) using a German sample [30]. In UK Keeley et al. has designed and validated an assessment tool "Lymphedema quality of life" (LYMQOL) that consists of two questionnaires, one for patient with upper-limb edema and one for lower-limb edema, the second focuses on chronic edema in general [31].

Due to the special symptoms and problems of the patients with LE, it is important to use a questionnaire developed especially for this group [9]. The only disease-specific HRQL-instrument that assesses HRQL in patients with different kinds of LE that is tested for validity and reliability thus far is the Swedish Lymphedema Quality of Life Inventory (SLQOLI) [32], originally developed and tested for validity in Australia, presented at the Australian Lymphology Association 5th biennial conference Brisbane, Australia, 2004. When adapted for use with Swedish patients, content and face validity was assessed by a panel of experts (n=11) and patients with different types of LE (n=16). During this process three items were added.

The SLQOLI consists of 61 perceived concerns (items) structured as four domains: physical, emotional, social and practical concerns (Table 1). Respondents are asked to think about these concerns over the past four weeks and respond to three questions: "How much do these concerns affect your quality of life?", "How many changes have you had to make in your everyday life because of these concerns?" and "How difficult have these changes been for you?" Responses to these questions are structured as a 4-point Likert scale ranging from 0 (no effect on HRQL) to 3 (a large effect on HRQL). The questionnaire also includes four items about general HRQL, two of them are structured as a 10 point-Likert-type scale and one is an open-ended item.

Test-retest reliability of the questionnaire was assessed using 58 Swedish patients with LE and demonstrated moderate reliability and was judged to be valid [32]. However, the instrument was lengthy, creating a burden for patients to complete. The time needed to complete the form varied from 15 minutes to 2 hours and 40 minutes (median = 30 minutes). Therefore, it was deemed appropriate to develop and test an abbreviated instrument based on the SLQOLI for use in both clinical and research settings. The aim of this study was first to reduce the SLQOLI to an abbreviated, clinically useful version while at the same time trying to keep the original structure (phase 1) and then test it for reliability and validity (phase 2).

Methods

Phase 1

Development of the Abbreviated SLQOLI

Results from the reliability testing of the SLQOLI were used for the item reduction phase of the study. Subjects included 50 consecutive patients from each of the Lymphedema Units at Skåne University Hospital, Lund and the Red Cross Hospital, Stockholm, Sweden. Fifty-eight patients completed the SLQOLI twice [32].

We examined whether it was necessary to include all three questions with respect to the 61 items.

Factor analysis, a principal component analysis followed by varimax rotation, was used to analyze the correlations among items in response to the first question. Spearman´s rank correlation coefficients (r_s) [33] were used to examine correlations between responses to the three questions. Factor analysis was performed first on each domain separately. Because some items were phrased in similar ways across the emotional and social domains, a factor analysis was also performed with these two domains merged.

Results of the factor analysis were examined by two physiotherapists with long clinical practice and experience within the lymphology area, considered to reduce, merge and if relevant also to carefully rename the items. The reduction process and the results were presented to a lymphedema expert group, including four physiotherapists, four enrolled nurses, two occupational therapists, and a social worker with extensive experience working with patients with LE and knowledge of questionnaire design. Nine of the expert group members were also lymph therapists. All were asked to check and relate their experience of their patient's relation to lymphedema and quality of life.
The outcome of phase 1 was a 45-item LyQLI.

Phase 2

Reliability and Validity Testing of the Abbreviated Scale

A consecutive sample of 200 out patients (100 per study site) was selected from the registers of the Lymphedema Units at Skåne University Hospital, and from the Red Cross Hospital, Solna, Sweden. Adults, eighteen years and older, diagnosed with lymphedema for at least six month, and who understood Swedish verbally and in writing were included.
Stratified selection was used to recruit the following sub-groups: secondary LE in the upper-limbs/head and neck (n=80), secondary LE in the lower limbs/genitalia (n=60), and primary LE (n=60). The selection is consistent with the incidence of LE patients at both clinics.

Patients' with secondary upper-limbs LE had to have volume differences of 10 % or more [34]. Cases of lower-limb edema that had developed secondary to medical conditions such as cardiovascular and renal disease, venous thrombosis, and end-stage recurrent malignancy, patients with mental disease and in-door patients involved in intensive LE treatment during the test period were excluded. In Sweden intensive LE treatment is often performed in periods of one to three weeks, depending on the severity of the LE. Treatments include; daily wrapping with non-elastic bandages, manual lymphatic drainage, skin-care, physical training, intermittent pneumatic etc. [2-5].

Procedure
The 45-item LyQLI (Appendix) was mailed to the patients, along with a consent form, a demographic questionnaire and the SF-36. All persons gave their informed consent prior to the inclusion and they were informed that identity details should be omitted. A reminder letter was sent after one week to patients who had not responded. Directly after the first response was received, the questionnaire was sent again to achieve no more than a two-week time gap between the two tests. It was expected that the time gap would be long enough to avoid memory effects. No additional treatment should be given within this time frame to interfere with stability over time testing. If the patient did not reply to the second test, a reminder was sent after one week. Patients who still did not respond to the second test were contacted by telephone, to make sure that they had received the questionnaire. The test period was April - June 2012.

An additional nine patients answered the LyQLI while attending the Lymphedema Unit in Solna and the length of time for completion of the instrument was recorded.

Statistical analysis

Systematic disagreement between the two tests occasions was evaluated using the relative position (RP) [35]. For each item the cumulative frequencies from the second test were plotted against the cumulative frequencies from the first test; the points were combined to ROC-curves [35]. Deviations from the diagonal line were signs of systematic changes. The ROC-curves belonging to the same domain were plotted with one diagram for each domain. The Wilcoxon signed rank test was used to test if the disagreements measures RP within each domain differed statistically significant from zero ($p < 0.05$).

Test-retest reliability was evaluated for each of the three domains using the Intraclass Correlation Coefficient (ICC) together with a 95 % confidence interval, using two-way random effect models with absolute agreement. We predetermined that patients with more than five missing responses were considered drop-outs and their data would not be used. We further determined that for respondents with fewer than five missing response, a mean score for each domain for each patient would be imputed missing values. Test-retest reliability was evaluated by calculating possible systematic changes in the domain scores. For each domain, the differences in score between the two test occasions were calculated and tested using student's t-test. Cronbach's alpha coefficients were calculated to estimate the internal consistency of each of the three domains.

Concurrent validity was assessed using Spearman's rank correlation coefficients (r_s) [36] to assess concordance of scores of the three domains of LyQLI and the scores of the two sum scores Physical Health (PCS) and Mental Health (MCS) in the SF-36 [18]. Possible floor and ceiling effects in the items were studied by examining skewness characteristics. A skewness value close to zero was used to indicate that there was neither a floor -nor a ceiling effect. IBM SSPS Statistics 20 was used for statistical analysis and significance values of < 0.05 were pre-set to indicate statistical significance.

The study was approved by the Research Ethics Committee, Lund University, Sweden, Dnr 2012/146 in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

Results

Phase 1

Development of the Abbreviated SLQOLI

Results from the Spearman´s rank correlation coefficient tests revealed high correlations between responses to the first question concerning HRQL and the two other questions about these items ($r_s > 0.60$ for all four domains, see Table 2). Therefore, second and third questions were judged to be redundant and were removed.

As a result of the factor analysis and the experience based reduction, the four domains (physical, emotional, social and practical) were reduced to three (physical, psychosocial and practical). In the physical domain the number of items was reduced from 17 to 12 (Figure 1). For the emotional and social domains the number of items was reduced from 26 to 16 and the two domains were merged to one, relabeled the psychosocial domain (Figure 2). The practical domain was reduced from 18 to 13 items (Figure 3) and the open-ended item was removed because responses indicated that the item did not provide new information. In total, the number of items was reduced from 188 to 45. A small modification in the sequence of the items at the last page was made and the two items with 10 point-Likert-type scale response options were changed to a 4 point-Likert scale to avoid confusion.

The lymphedema expert group and the social worker judged the abbreviated scale to have good face validity and the new questionnaire, with vertically arranged items on an A4 paper to be an improved format resulting in the abbreviated Lymphedema Quality of Life Inventory (LyQLI) (see Appendix).

Phase 2

Reliability and Validity Testing of the Abbreviated Scale

Two hundred questionnaires were mailed to patients. One patient notified that she no longer had a LE and was excluded because she did not fulfill inclusion criteria. One hundred and thirty one patients agreed to participate of them 126 patients (97%) completed test 1 and test 2, their characteristics are shown in Table 3. Seventy-three patients did not complete the two questionnaires for different reasons shown in Figure 4. Characteristics for these drop-outs are shown in Table 3. Median time between the two completed tests was 10 days (range=1-144 day, 25th to 75th percentile: 7 to 14 days). Median time to complete the form was 6 minutes (range=5-11).

There were few internal missing values. At the initial testing time the maximum number of missing values for physical/psychosocial/practical domains were 4, 1, and 2 respectively; and for the retest responses the number of missing values for these three domains was 3, 2, and 5. For all 41 items, the percentage of missing items for the patients varied between 0 to 14.6 % for both tests, 25th to 75th percentile: 0.0 to 0.2 % for test 1 and 0.0 to 0.0 % for test 2. For these patients the mean score was imputed. Given the small number of internal missing values there were no missing domain scores.

Systematic disagreements between test 1 and test 2 were calculated using the disagreement measure RP and are illustrated by receiver characteristic curve (ROC) for items belonging to the same domain (Figure. 5-7) [35]; the mean RP in the physical domain was -0.059, in the psychosocial -0.031, and in the practical -0.035. For all three domains a small systematic statistical significant change was seen towards higher HRQL.

Assessment of responses indicated that there was a statistically significant change in reporting between test one and two, with lower scores for each domain at test 2 (Table 4). All three mean differences differed significantly from zero. This difference was also found for the overall quality of life items 44 and 45. In the physical and psychosocial domain ICC was 0.88 ($p < 0.01$) and in the practical 0.87 ($p < 0.01$). Cronbach's alpha coefficients of 0.88, 0.92, and 0.88 were obtained for each of the three domains respectively.

One hundred and thirty patients completed test 1, all of them except for one also completed SF-36. There were four (3 %) missing values in each of PCS and MSC. The correlation between the score in the three domains of LyQLI and the two sum scores PCS and MCS in SF-36 is shown in Table 5. Correlations are negative because high values in LyQLI indicate low HRQL which is the opposite for SF-36. Therefore, results provide evidence of concurrent validity of the LyQLI.

Table 6 shows the distribution of skewness characteristic, whether they are not significantly different from zero, and how many that is positively and negatively skewed. Results reveal a tendency towards a small floor effect.

Discussion

The purpose of this study was to reduce SLQOLI to develop and test a shorter instrument for use in clinical practice and research with less subject burden. LyQLI has been developed and the items that were retained measure physical, psychosocial and practical problems that patients with LE experience and which may affect their HRQL [9-11]. Results were consistent with opinions from the expert group and the social worker. A limitation in this study may be that we have no patient expert group looking over the final version of the questionnaire for the comprehensiveness of the items. However, the items that were retained were mostly not changed, just fewer in number. Small changes included merging two items, "pain due to my lymphedema" and "aches due to my lymphedema" into one item "Pain/aches due to my lymphedema" (Figure 1) and "feelings of frustration" and " feeling annoyed" into "feeling of frustration/feeling annoyed" (Figure 2). Our hypothesis was that this would make it easier for the patients, thou they did not have to distinguish between two relatively equally items. The reduction was based on Spearman's correlation coefficients and factor analyses, and reliability of the abbreviated instrument was then examined using appropriate statistics [33].

Phase 1

Development of the Abbreviated SLQOLI

As a result of the correlation analysis in phase 1, the three questions pertaining to the items were reduced to one. The SLQOLI consists of 188 items and the LyQLI of just 45. One reason to only retain the question referring to HRQL was that many patients have had the LE for a long time (median = 7 years) and may have difficulties relating to items about changes in everyday life. In addition, patients with primary LE may have had the edema from birth or from very young years, with no other experience to compare.

The four domains (physical, emotional, social and practical) were reduced to three (physical, psychosocial and practical) with agreement from the expert panel to merge the emotional and social domains, although there were several items that were similar and were difficult to classify. The median time for patients to complete the abbreviated form was 6 minutes, compared with 30 minutes for the original questionnaire, providing evidence for the feasibility and practicality of the shorter questionnaire.

Phase 2

Reliability and Validity Testing of the Abbreviated Scale

Characteristics of the 126 patients who completed the two questionnaires as well as the 73 who withdrew are shown in Table 3. The two groups did not differ according to age, sex, year with LE and type of LE (secondary/primary). The interval between test one and two was as intended (median=10 days). It is recommended that the time gap between the repeated administrations should be long enough to prevent recalls, though short enough to ensure that clinical change has not occurred. Often, 1 or 2 weeks will be appropriate [37]. The median time for patients to complete the new form was 6 minutes and for the original questionnaire 30 minutes. The patients were recruited from out-door units, which means that they are in contact with the clinic regularly. This may imply that they are cared for in a better way than patients having less frequent contact to the clinic. Patients seeking more contact may, on the other hand, be those who have more severe LE. However, it may be the opposite, that patients have less contact because they feel better. Thus we estimate that patients taking part in this study are representative for LE patient with both small and large lymphedema problems. Patients with edema developed secondary to medical conditions such as cardiovascular and renal disease, venous thrombosis, and end-stage recurrent malignancy were not included so the study population is not representative for patients with such comorbidities.

Systematic disagreements between test 1 and test 2 were calculated using the disagreement measure RP for the three domains and for the two overall quality of life items. A minute systematic change towards increased HRQL was found for all indicators of HRQL. The mean improvement in the three domains is shown in Table 4. Because there was no intervention between the two test occasions, no improvement was expected. One explanation for the change may be that the test-retest period was set in a spring time period. In Sweden the winter is dark and often cold. Spring brings light and warmer weather and therefore the patients' general quality of life may have increased.

Another explanation may be an *expectations effect.* Participants who participated in a study may have felt that some results/change were expected; with a social desirability factor prompting patients to rate their HRQL more positively the second time tested [38]. It is also possible that the time interval between tests one and two was too long and that the phenomenon being tested changed over this time period (10 days). This improvement between the two test occasions has to be taken into consideration when using the LyQLI during an intervention.

In the physical and psychosocial domain ICC was 0.88 ($p < 0.01$) and in the practical 0.87 ($p < 0.01$). An ICC > 0.70 is considered as good [33]. Cronbach's alpha coefficients of 0.88, 0.92, and 0.88 for each of the three domains were obtained. An alpha value 0.70 - 0.95 is considered to be a very good estimate of internal consistency reliability [37].

According to Fayers and Machin concurrent validity involves assessing an instrument against the true value or if no true value is available to a *gold standard* [13]. In this study the well-established questionnaire SF-36 was chosen because it is a widely used generic HRQL instrument both in Sweden and worldwide, with demonstrated validity and reliability [17-19]. However, because the SF-36 was not developed for this specific study population, we estimated that the sum scores for PCS and MCS in SF-36 should be at least reasonably highly correlated with the three domains in the LyQLI to confirm concurrent validity. The correlation coefficient between the physical and practical domain in the LyQLI and PCS in the SF-36 was moderate; the correlation coefficient between the physical and psychosocial domain in the LyQLI and MCS was low, and the correlation coefficient between practical domain and MCS was moderate [39]. These results provide evidence to support the concurrent validity of the abbreviated instrument.

Conclusion

The aim of this study was to reduce the 188-item SLQOLI to an abbreviated, clinically useful version and test it for reliability and validity. LyQLI is shorter with 45 items instead of 188. The median time to complete the form was reduced from 30 minutes to 6 minutes. LyQLI demonstrated good internal consistency reliability and face and concurrent validity. Further research to assess the sensitivity of the LyQLI is warranted. However, the instrument shows promise for evaluations of quality of life in clinical settings and in future cross-sectional studies to increase understanding and test interventions aimed at assisting patients with LE.

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Captions

Table 1 Swedish Lymphedema Quality Of Life Inventory consists of three questions each having four answer alternatives

Table 2 Frequency distributions of the correlations between the first question and the two others (Table 1)

Table 3 Characteristics of patients that participated (n=126) and drop-outs (n=74)

Table 4 Test-retest scores and differences in the Lymphedema Quality of Life Inventory (n=126). All factors have possible values in the interval (0, 3).

Table 5 Correlations between the two sum scores Physical Health and Mental Health in SF-36 and the three domains in the Lymphedema Quality of Life Inventory (n=129)

Table 6 Skewness characteristics

Fig. 1 Items in the physical domain that remained, were reworded or were merged.

Fig. 2 Items in the emotional and social domains that remained, were reworded or were merged into the psychosocial domain

Fig. 3 Items in the practical domain that remained, were reworded, reduced or merged

Fig. 4 Flow chart of participants in test-retest of the Lymphedema Quality of Life Inventory

Fig. 5 ROC-curve for the physical domain, each line represents one item and the paired answers in test-retest on group level

Fig. 6 ROC-curve for the psychosocial domain, each line represents one item and the paired answers in test-retest on group level

Fig. 7 ROC-curve for the practical domain, each line represents one item and the paired answers in test-retest on group level

LYMPHEDEMA QUALITY OF LIFE INVENTORY (LyQLI)-Development and investigation of validity and reliability

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How much do these concerns affect your quality of life?	No effect	A Little	A Bit	A Lot
How many changes have you had to make in your everyday life because of these concerns?	No changes	Few	Some	Many
How difficult have these changes been for you?	Not difficult	Some	Very	Extremely

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Domain	**r_s = 0.60-0.69**	**r_s = 0.70-0.79**	***r_s = 0.80-0.89***	**r_s = 0.90-1.00**	***Total$_s$ 0.6-1.00***
Physical	12 %	41 %	20 %	26 %	100 %
Emotional	6 %	28 %	44 %	16 %	100 %
Social	0 %	20 %	25 %	55 %	100 %
Practical	0 %	11 %	56 %	33 %	100 %

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Characteristics	**Test-retest**	**Drop-outs**
Age, years, median (range)	62 (19-92)	58 (20-91)
Year with lymphedema, median (range)	7 (0-70)	6 (0-87)
Women /men, no (percentage)	110/16 (87/13)	58/16 (78/22)
Lymphedema secondary/primary, no (percentage)	93/33 (74/26)	50/23 (68/32)
Edema of the lower limbs/upper limbs/others, no (percentage)	70/50/6 (55/40/5)	45/23/5 (62/31/7)

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Domain	**Test 1** Mean (95 % CI)	**Test 2** Mean (95 % CI)	**Difference** Mean (95 % CI)
Physical	1.13 (1.02 - 1.24)	1.03 (0.93 – 1.13)	0.10 (0.05 - 0.14)
Psychosocial	0.89 (0.78 – 1.00)	0.83 (0.73 – 0.94)	0.06 (0.01 – 0.11)
Practical	1.00 (0.89 – 1.11)	0.93 (0.82 – 1.03)	0.07 (0.02 – 0.13)

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SF-36 sum score	**LyQLI**		
	Physical domain	Psychosocial domain	Practical domain
Physical Health (PCS)	-0.578**	-0.285**	-0.533**
Mental Health (MCS)	-0.389**	-0.469**	-0.510**

**Correlation is significant at the 0.01 level (2-tailed)

LYMPHEDEMA QUALITY OF LIFE INVENTORY (LyQLI)-Development and investigation of validity and reliability

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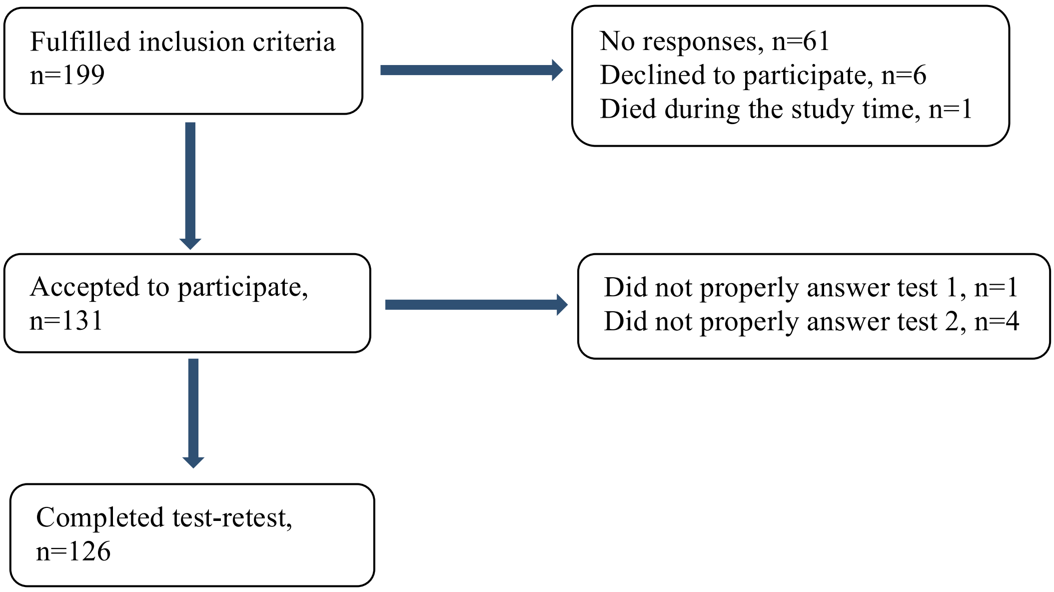
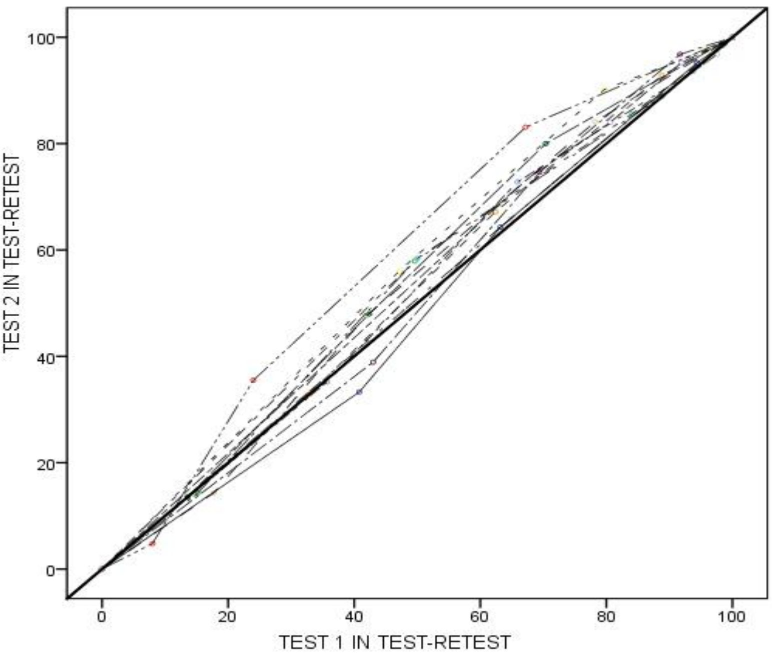
Domain	Skewness not significantly different from 0	Skewness significant positive	Skewness significant negative
Physical items (n=12)	6	5	1
Psychosocial items (n=16)	5	11	0
Practical items (n=13)	4	9	0
Sum items (n=41)	15	25	1

Original version (SLQOLI) 17 items in physical domain	Reduced version (LyQLI) 12 items in physical domain
1. Pain due to my lymphoedema 2. Aches in my limb	1. Pain/aches due to my lymphedema
3. Discomfort in my limb	2. Discomfort due to my lymphedema
4. A feeling of heaviness in my limb	3. A feeling of heaviness due to my lymphedema
5. Pins and needles in my limb 7. Numbness due to my lymphoedema	4. Pins and needles/numbness due to my lymphedema
6. Burning sensation due to my lymphoedema 11. Feeling of heat from my limb	5. Burning sensation/heat due to my lymphedema
8. A feeling of tightness in my limb 9. Swelling of my limb	6. Swelling/tightness due to my lymphedema
10. Skin problems due to my lymphoedema	7. Skin problems due to my lymphedema
12. Needing to reposition myself to sleep 13. Difficulty sleeping due to my limb	8. Difficulty sleeping due to my lymphedema
14. Movement difficulties due to my lymphoedema	9. Movement difficulties due to my lymphedema
15. Feeling conscious of my limb all the time	10. Feeling physically aware of my lymphedema all the time
16. Feeling a loss of power in my limb	11. Feeling a loss of strength in the swollen part of my body
17. Cellulitis	12. Infection (e.g. cellulitis, erysipelas)

Original version (SLQOLI) 16 items in emotional domain and 10 items in social	Reduced version (LyQLI) 16 items in psychosocial domain
18. Feelings of frustration 19. Feeling annoyed 23. Irritated by the inconveniences	13. Feelings of frustration/feeling annoyed
20. Feeling anxious about whether or not the lymphoedema will get worse	14. Feeling anxious about whether or not the lymphedema will get worse
21. Embarrassed by lymphedema 40. Feeling self-conscious about my limb	15. Embarrassed by lymphedema/compression garments
22. Changes in how I see myself	16. Negative changes in how I see myself
25. Feeling discouraged	17. Feeling discouraged
24. Not accepting the situations I have to avoid (e.g. sun, recreational activities) 43. Not being able to do the things I used to	18. Not being able to do the things I used to enjoy
26. Worrying about what is safe to do 27. Concern about when to seek medical	19. Concerns about when to seek medical attention
28. Paying constant attention to my condition 29. Coping with the ongoing nature of	20. Paying constant attention to my condition
30. Concerns about how my lymphoedema affects my relationships	21. Concerns about how my lymphedema affects my existing relationships
33. Concerns about how lympheodema could affect new relationships	22. Concerns about how lymphedema could affect new relationships
31. Changes in my feelings about intimacy 32. Changes in my feelings about sexuality	23. Negative changes in my feelings about intimacy/ sexuality
34. Needing to make changes to sporting activities (e.g. swimming, tennis) 35. Needing to be more careful when doing	24. Feeling uncomfortable/embarrassed while doing sports and hobbies
36. Concerns about attending special social occasions (e.g. weddings, celebrations) 37. Concerns about attending outdoor social activities (e.g. picnics in the sun)	25. Feeling uncomfortable/embarrassed while attending social activities with friends and at
38. Having to ask for help from family and friends (e.g. carrying groceries)	26. Having to ask for help in different situations
41. Concerned about changes in my appearance	27. Concerns about negative changes in my appearance
42. Having to answer questions about my limb	28. Having to answer questions about my lymphedema

Original version (SLQOLI) 18 items in practical domain	Reduced version (LyQLI) 13 items in practical domain
44. Personal activities of daily living (e.g. dressing, combing hair, brushing teeth	29. Personal activities of daily living (e.g. dressing, combing hair, foot care)
45. Normal daily activities (e.g. doing housework)	30. Normal daily activities (e.g. doing housework, sports- and hobby activities)
46. Change of diet	
47. Employment activities (e.g. unable to do the work, or the amount of time required)	31. Employment activities
48. Learning to do things differently	32. Learning to do things differently
49. Having less energy to do activities (e.g. personal, normal daily, or employment) 50. Feeling fatigued after completing activities (e.g. personal, normal daily, or employment)	33. Having less energy to do activities (e.g. personal, normal daily or employment)
51. Is the number of activities you do in one day reduced	
52. The need to priorities the activities you can do.	
53. Financial costs of managing my lymphoedema (e.g. garments, treatments)	34. Financial costs of managing my lymphedema (e.g. clothes, shoes, treatments, garments)
54. Concern about finding good compression garments	35. Finding well-functioning compression garments (e.g. stockings, sleeves, gloves)
55. Driving a car	36. Traveling long distances by car, train, plane etc
56. Finding clothes that are comfortable, the right size and type of material	37. Finding clothes and shoes that are comfortable and attractive, the right size and type of material
57. Needing to cover up in the sun	38. Limitations in hot weather/sunshine
58. The constant self-care I need to do to stop my lymphoedema from getting worse 59. The time required to manage lymphoedema	39. The constant self-care I need to do to stop my lymphedema from getting worse
60. Obtaining information about how to manage my lymphoedema	40. Obtaining information about how to manage my lymphedema
61. Being prepared for emergencies (e.g. carrying first aid equipment, always having a script for antibiotics)	41. Being prepared for emergencies (e.g. always having a script for antibiotics)


Fulfilled inclusion criteria n=199
No responses, n=61
Declined to participate, n=6
Died during the study time, n=1
Accepted to participate, n=131
Did not properly answer test 1, n=1
Did not properly answer test 2, n=4
Completed test-retest, n=126


TEST 2 IN TEST-RETEST
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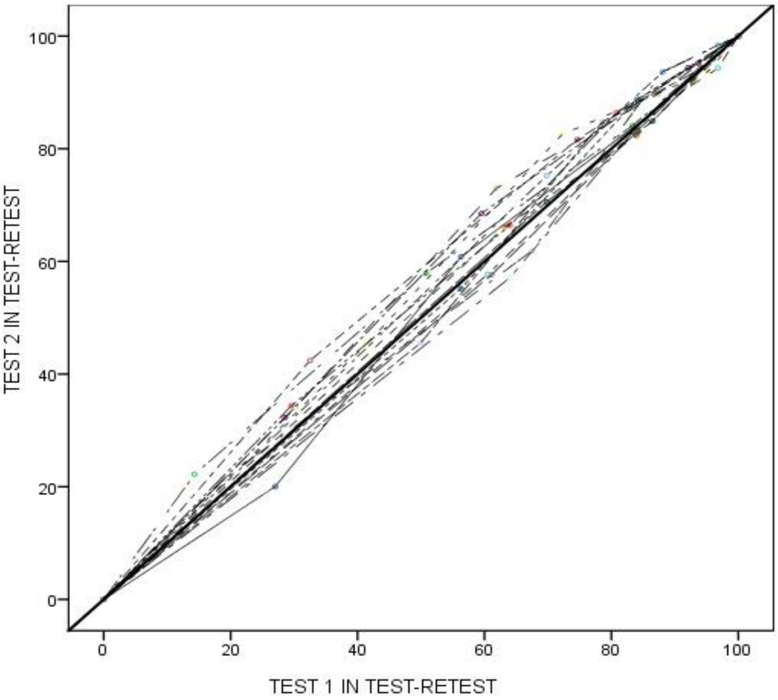
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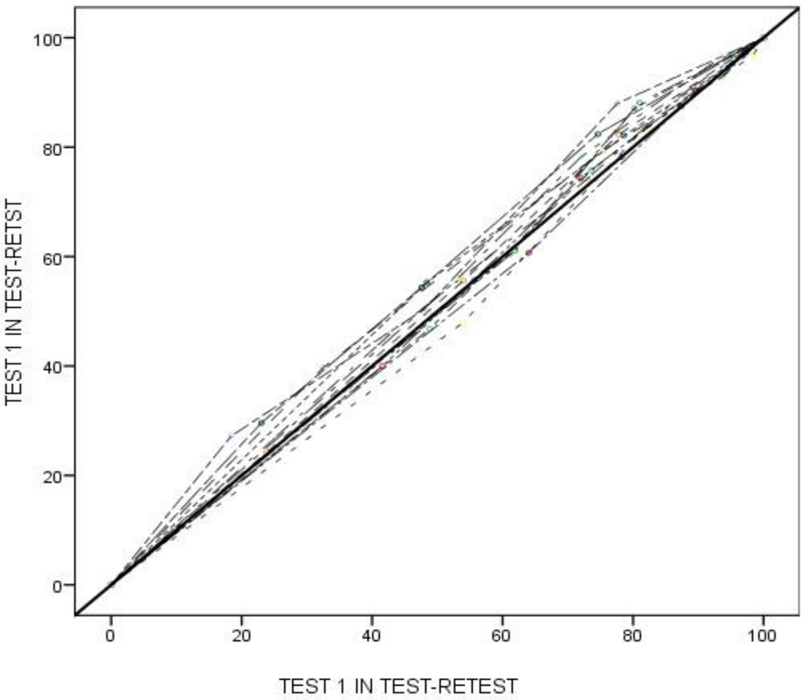
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Lymphedema Quality of Life Inventory (LyQLI)

This questionnaire is concerned with the way lymphedema may affect your quality of life and activities of daily living.

You may have experienced very mild lymphedema, moderate or severe symptoms. You may have lived with your symptoms for a short or long period of time.

Please answer these questions only as they concern your lymphedema

The questionnaire consists of three parts

- Physical
- Psychosocial
- Practical

Please think about your Lymphedema and your Quality of Life during **the past four weeks**. When it comes to questions that depend on seasons, think about the **past year**.

For each question circle the answer that best matches your experiences. **Try to answer all questions. If a question does not seem to apply to you, please circle the choice that says "None"**

	Physical concerns due to lymphedema	How much do these concerns affect your quality of life?			
1	Pain/aches due to my lymphedema	None	A little bit	Somewhat	A lot
2	Discomfort due to my lymphedema	None	A little bit	Somewhat	A lot
3	A feeling of heaviness due to my lymphedema	None	A little bit	Somewhat	A lot
4	Pins and needles/numbness due to my lymphedema	None	A little bit	Somewhat	A lot
5	Burning sensation/heat due to my lymphedema	None	A little bit	Somewhat	A lot
6	Swelling/tightness due to my lymphedema	None	A little bit	Somewhat	A lot
7	Skin problems due to my lymphedema	None	A little bit	Somewhat	A lot
8	Difficulty sleeping due to my lymphedema	None	A little bit	Somewhat	A lot
9	Movement difficulties due to my lymphedema	None	A little bit	Somewhat	A lot
10	Feeling physically aware of my lymphedema all the time	None	A little bit	Somewhat	A lot
11	Feeling a loss of strength in the swollen part of my body	None	A little bit	Somewhat	A lot
12	Infection (e.g. cellulitis, erysipelas)	None	A little bit	Somewhat	A lot

	Psychosocial concerns due to lymphedema	**How much do these concerns affect your quality of life?**			
13	Feelings of frustration/feeling annoyed	None	A little bit	Somewhat	A lot
14	Feeling anxious about whether or not the lymphedema will get worse	None	A little bit	Somewhat	A lot
15	Embarrassed by lymphedema/compression garments	None	A little bit	Somewhat	A lot
16	Negative changes in how I see myself	None	A little bit	Somewhat	A lot
17	Feeling discouraged	None	A little bit	Somewhat	A lot
18	Not being able to do the things I used to enjoy	None	A little bit	Somewhat	A lot
19	Concerns about when to seek medical attention	None	A little bit	Somewhat	A lot
20	Paying constant attention to my condition	None	A little bit	Somewhat	A lot
21	Concerns about how my lymphedema affects my existing relationships	None	A little bit	Somewhat	A lot
22	Concerns about how lymphedema could affect new relationships	None	A little bit	Somewhat	A lot
23	Negative changes in my feelings about intimacy/sexuality	None	A little bit	Somewhat	A lot
24	Feeling uncomfortable/embarrassed while doing sports and hobbies	None	A little bit	Somewhat	A lot
25	Feeling uncomfortable/embarrassed when attending social activities with friends and at work	None	A little bit	Somewhat	A lot
26	Having to ask for help in different situations	None	A little bit	Somewhat	A lot
27	Concerns about negative changes in my appearance	None	A little bit	Somewhat	A lot
28	Having to answer questions about my lymphedema	None	A little bit	Somewhat	A lot

	Practical concerns due to lymphedema	**How much do these concerns affect your quality of life?**			
29	Personal activities of daily living (e.g. dressing, combing hair, foot care)	None	A little bit	Somewhat	A lot
30	Normal daily activities (e.g. doing housework, sports- and hobby activities)	None	A little bit	Somewhat	A lot
31	Employment activities	None	A little bit	Somewhat	A lot
32	Learning to do things differently	None	A little bit	Somewhat	A lot
33	Having less energy to do activities (e.g. personal, normal daily or employment)	None	A little bit	Somewhat	A lot
34	Financial costs of managing my lymphedema (e.g. clothes, shoes, treatments, garments)	None	A little bit	Somewhat	A lot
35	Finding well-functioning compression garments (e.g. stockings, sleeves, gloves)	None	A little bit	Somewhat	A lot
36	Traveling long distances by car, train, plane etc.	None	A little bit	Somewhat	A lot
37	Finding clothes and shoes that are comfortable and attractive, the right size and type of material	None	A little bit	Somewhat	A lot
38	Limitations in hot weather/sun	None	A little bit	Somewhat	A lot
39	The constant self-care I need to do to stop my lymphedema from getting worse	None	A little bit	Somewhat	A lot
40	Obtaining information about how to manage my lymphedema	None	A little bit	Somewhat	A lot
41	Being prepared for emergencies (e.g. always having a script for antibiotics)	None	A little bit	Somewhat	A lot

42. In terms of your lymphedema, has this been a typical four week period for you?

Yes ( )   No ( )

43. If you answered "No" to the question above, has this period been (tick one)

Much Worse ( )   Worse ( )   Better ( )   Much Better ( ) than usual

44. Please think about how your lymphedema has affected you in the past four weeks and circle the number below that best matches your experience with lymphedema.

0	**1**	**2**	**3**
Very bad			**Very good**

45. Taking all parts of your life into consideration, how would you describe your quality of life in the past four weeks? Please circle the number below that best matches your overall quality of life.

0	**1**	**2**	**3**
Very bad			**Very good**

Thank you for your time completing this questionnaire!