Lymphology 43 (2010) 135-145

ASSESSMENT OF QUALITY OF LIFE IN LYMPHEDEMA PATIENTS: VALIDITY AND RELIABILITY OF THE SWEDISH VERSION OF THE LYMPHEDEMA QUALITY OF LIFE INVENTORY (LQOLI)

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ABSTRACT

The Lymphedema Quality of Life Inventory (LQOLI) is an instrument developed for patients with different types of lymphedema. It contains physical, emotional, social, and practical dimensions and consists of 58 items, each with three sub items concerning life quality, daily life changes, and difficulties of changing and two items concerning life quality in general and in relation to lymphedema. The purpose of this study was to adapt the Australian LQOLI to Swedish conditions and to test it for clarity, face validity, content validity, construct validity, and reliability. Content and face validity was completed by experts (n=11) and patients with different types of lymphedema (n=16). For construct validation the SF-36 (n=63) was used. Test-retest reliability was evaluated with lymphedema patients (n=58) answering the questionnaire twice, within median 3 weeks. Three items were added in the Swedish version of LQOLI (SLQOLI). The kappa coefficients in test-retest for all items and sub items varied (range=0.25-0.83). Construct validity showed moderate correlation with SF-36. The SLQOLI is adapted and valid, with moderate reliability, and it can be used in clinic to describe life quality for patients with lymphedema. In this study, 67% of the patients experienced an effect on life quality within the physical dimension and 54-58% within the emotional, social, and practical dimensions.

Keywords: lymphedema, health-related quality of life, reliability, validity

Lymphedema can be defined as tissue fluid accumulation in one or more of the limbs, and it can also manifest in other organs. Lymphedema arises as a consequence of impaired lymphatic drainage and can be classified into primary and secondary lymphedema (1). Lymphedema is a chronic condition which requires lifelong treatment. It may vary from mild to severe, and without adequate treatment it can result in several complications as massive edema, lymphangitis/cellulitis, impaired limb function, psychosocial disability, and even malignant complications (1,2). Lymphedema therapy includes conservative treatment like manual lymphatic drainage, intermittent pneumatic compression, fitting with non-elastic wrappings and/or compressive garment (1-4), as well as surgical treatment like liposuction (5).

The etiology of *primary lymphedema* is not well known, however, several anatomic defects can lead to lymphatic stasis, including

lymphatic hypoplasia or absence of lymphatic valves. Some patients may have impairment in the intrinsic contractility of the lymphangion (1). Swelling usually involves only one lower extremity, but multiple limbs, genitals, the face and even other organ can be involved (1). Three types of primary lymphedema have been recognized: *congenital* where the symptoms are present at birth or recognized within 2 years of birth; *praecox* the most common subtype which begins either at puberty or by the beginning of the third decade of life; and *tarda* which occurs after the age of 35 years. Lymphedema praecox and tarda are more common in females, while congenital is more likely to inflict males (1).

Secondary lymphedema is much more frequent than primary lymphedema, and occurs as a consequence of damage on the lymph system by surgery, severe trauma, and cancer treatment (1) which, in the Western society, is the most common cause of secondary lymphedema. Arm lymphedema most frequently follows axillary lymph node dissection related to breast cancer or melanoma. The incidence varies from about 5% to about 50% depending on surgical technique and adjuvant treatment but also on type of measurements and varying definition of lymphedema (3). Lymphedema of the lower limb may occur similarly after a melanoma, pelvic, or genital cancer operation. The reported frequency varies between about 5% and more than 60%, with likelihood of occurrence greater if there has been inguinal/pelvic lymph node dissection and/or irradiation (3).

The tropical filarial parasite is the most common cause of lymphedema globally. This enormous health problem impacts at least 120 million peoples in at least 83 countries (6,7).

Health, Quality of Life and Health Related Quality of Life

The World Health Organization has declared health to be "a state of complete physical, mental and social well-being and not merely the absence of disease" (8,9). Many other definitions of both "health" and "quality of life" exist, and in the absence of any universally accepted definition, some scientists argue that most people, in the Western world at least, are familiar with the expression "quality of life."

Traditional treatments cannot always cure chronic disease or appease the symptoms. For example, therapeutic interventions in cancer diagnoses frequently cause serious side-effects and impairment, and for some patients the experience of treatment can be worse than the illness itself. Under these circumstances it seems important to focus on quality of life (QOL) (8). To distinguish between QOL in its more general sense and the requirements of clinical medicine and clinical trials the term "health-related quality of life" (HRQOL) is used (8).

The definition of HRQOL is not concrete, "it is generally agreed that the relevant aspects may vary from study to study, but can include general health, physical functioning, physical symptoms and toxicity, emotional functioning, cognitive functioning, role functioning, social well-being and functioning, sexual functioning, and existential issues" (8). It is possible to use a more global question as "How would you rate your overall quality of life?" However, this sort of question is often regarded as too vague and non-specific to be used on its own. Instead, general questions may be combined into more specific survey instruments which include the aspects above (8). In the absence of any agreed upon formal definition of QOL and HRQOL, the investigator may define their own meaning of these expressions in questions to the patient.

A widely used generic HRQOL instrument, that is reliable and valid, is the SF-36 (9-12). The SF-36 measures eight health-related domains and contains 36 items (13).

Lymphedema and Health Related Quality of Life

Traditionally lymphedema has been

regarded as an unimportant complication of essential life-saving treatment for cancer. Recently lymphedema has been recognized as a complex problem that can strongly influence HRQOL (14). When some patients recognize that lymphedema is a chronic disease, they may get depressed and feel that the swelling limb is worse than the cancer itself is. Therefore, lymphedema may have severe consequences in the patient's life-social, mental and functional (14,15).

Johansson et al (16) found in a qualitative study of 12 breast cancer survivors with arm lymphedema in Sweden that the women had difficulties relating to attitudes in their surroundings and to the chronic disease. The women used problem- focused coping strategies as well as emotion-focused mechanisms to handle their situations (16). The study showed the importance of examining the practical, emotional and psychosocial problems experienced in daily life.

EORTC QLQ-BR32 (17) is a HRQOL-instrument that has been designed for people with different stages of breast-cancer. In a study by Pyszel et al (18) the questionnaire was completed by 283 breast cancer survivors in Poland. It was concluded that breast cancer survivors with arm lymphedema were more disabled, experienced a poorer quality of life, and had increased psychological distress in comparison to survivors without lymphedema (18). Wilson et al (10) found similar results in their study of 110 women treated surgically for breast cancer.

Jäger et al (9) investigated 40 women with lymphedema after breast-cancer and 40 women who had a trauma but were without lymphedema using "The Frankfurt Body Image Questionnaire" and "The RAND 36-Item Health Survey" (SF-36). Results of both instruments indicated that the women with lymphedema had a lower score both for body-image and quality of life (9).

Lower limb lymphedema was examined by Bogan et al (2) in a qualitative study. They found that people with non-cancer-related lymphedema in the lower limbs score their quality of life as low. In a literature review of 6 articles, Morgan et al (14) showed similar results. Franks et al (11) examined a number of HRQOL tools for lower limb lymphedema and found that SF-36 appeared to be the most appropriate for use in this patient group.

Sitzia & Sobrido (19) investigated whether conservative treatment resulted in significant changes in HRQOL in patients with primary or secondary lymphedema. Investigators used "the Nottingham Health Profile Part 1" (NHP-1), which contains 38 negative statements in six health dimensions (20). Study results showed that the change in limb volume in 37 patients was not associated with a change in any dimension of NHP-1, and investigators concluded the instrument was not sensitive enough (19).

Only one tool has been developed to measure HRQOL in specific for lymphedema, namely "Upper limb lymphedema 27 (ULL27)" including 27 questions in three domains (21).

A review by Morgan et al (14) concluded that the most often used measurements are either general or specific to certain cancers. Further, they found most studies have been done in women with arm lymphedema after cancer treatment. One potential reason for the lack of research involving patients with lymphedema in other parts of the body may be that no disease specific instrument exists to adequately measure quality of life in these patients. Due to the special symptoms and problems of the patients with lymphedema, it is important to use a HRQOL instrument developed especially for this group including all kinds of lymphedema. To date, no such instrument has been tested for validity and reliability in Sweden.

The Lymphedema Quality of Life Inventory

The Lymphedema Quality of Life Inventory (LQOLI) is an instrument developed and tested in Australia (Kristjanson, 2004, not published), that measures HRQOL in patients with different types of lymphedema. It was

developed in three stages. In Stage I, qualitative interviews were administered to women that had experienced lymphedema. The women were asked about how the lymphedema affected their quality of life and their activity of daily living. Content analysis of these interviews resulted in salient indicators to produce four dimensions of the questionnaires: physical, emotional, social, and practical. Stage II included tests for clarity, face validity, content validity, and apparent internal consistency and involved a panel of women and health professionals with experience in the treatment of lymphedema. In Stage III, 196 men and women with lymphedema in either upper or lower limbs completed the LQOLI to assess the scale's internal consistency correlation (ICC) and concurrent validity.

The instrument consists of several items divided into four dimensions: physical, emotional, social, and practical. Each item is followed by three sub items, with four answer alternatives. The first sub item, "How much do these concerns affect your quality of life?", can be answered with 'no effect,' 'a little,' 'a bit,' or 'a lot.' Sub item 2, "How many changes have you had to make in your everyday life because of these concerns?" can be answered with 'no changes,' 'few changes,' 'some,' or 'many.' Responses to sub item 3, "How difficult have these changes been for you?" include 'not difficult,' 'some,' 'very,' or 'extremely.' The last part in the inventory contains one item about general quality of life during the past week (item 1a) and one item about quality of life specific to the lymphedema during the past week (item 1b). Both items are on an eleven degree scale, 0 indicating 'poor' and 11 being the 'best possible.' The next item asks if the past week had been a typical week (item 2), and if not, whether it had been worse or better (item 2a). The last item is an open-ended question asking in which way the week had been different (item 2b).

In Sweden, there is a need for an instrument like the LQOLI to establish the patient's base for lymphedema care and to measure and monitor improvement in the treatment. The purpose of this study was to translate and adapt the Australian LQOLI to Swedish conditions and to test it for clarity, face validity, content validity, construct validity and reliability.

METHODS

Translation

The translation from English to Swedish was done by 3 individuals, not related to each other, with good knowledge in English and Swedish. They were all health professionals with experience of lymphedema patients. After translation the text was synthesized in consensus between the 3 translators. The translation back to English was made by a person born in an English speaking country with good knowledge in Swedish, with no medical education but personal experience with lymphedema. Comparison between the new and original English versions was made by the English translator in cooperation with one of the Swedish translators (22).

Validity Step 1

The content validity of the statements in the LQOLI was examined by a group of 11 experts (8).

Expert group: Two occupational therapists, eight physical therapists, all with lymphedema therapist education, and one doctor were in the group. All experts had long histories of experience in lymphedema assessment and treatment and were active in different treatment centers throughout Sweden.

Procedure: A list of all items in the LQOLI and some added questions were sent to the expert group. The added questions included which statements their patients normally use to describe their lymphedema problems, and if items had to be added or withdrawn.

Validity Step II

To continue the content validity and the face validity test 19 patients were ask to complete the LQOLI.

Patient group: A convenient sample of well-known patients was selected by three physiotherapists. Selection was strategically accomplished in regard to sex, age, time since lymphedema diagnosis, primary/secondary lymphedema, and affected part of the body in order to comprise a sample representative of lymphedema patients in Sweden. Patients were chosen from 3 Swedish hospitals to guarantee geographic inclusion of both thinly and densely populated areas.

Procedure: Patients were contacted by telephone and all 19 agreed to take part. They received information of the study and instructions on how to fill out the LQOLI and additional questions. The additional questions were concerning whether the instrument was easily understood, if changes should be made, and if the design was relevant, e.g., if the 2 last answer options were relevant considering the increased completion time.

Test-Retest and Validity Step III

Subjects: One hundred patients, 50 per study site, were consecutively included from the registers of the Lymphedema Units at Skane University Hospital, Lund, and from the Red Cross Hospital, Stockholm, Sweden.

Inclusions criterion: Adults, eighteen years and older, with a lymphedema diagnosis, and who understood Swedish verbally and in writing were included.

Exclusions criterion: Patients were excluded if involved in intensive lymphedema treatment during the test period.

The study was approved by the Research Ethics Committee, Lund University, Sweden, Dnr 606/2007.

Procedure: For the test-retest part of the study (8,23) the final version of the Swedish LQOLI (SLQOLI) was sent to the patients (n=100) twice, within 2 weeks. For the cross-sectional construct validity test (24), the SF-36 was also distributed at the first time as well as a questionnaire concerning characteristics. The SF-36 was chosen because it is a widely used generic HRQOL instrument that has been tested for validity and reliability (9-12). Items in the two instruments were compared for similarity. Seven items encompassing the physical, social and practical, and general quality of life dimensions were selected as being similar. Items in the SF-36 and LQOLI had different scales for answer alternatives. Therefore, a correction to the lowest number of alternatives was made for each item, to make the comparison possible.

One to two weeks after the first administration responses were received, the SLQOLI was sent out again. If the patient did not respond to the second administration, a reminder letter was sent after 2 weeks. The patients that still did not respond were contacted by telephone.

Statistical Analysis

SSPS version 14.0 was used for statistical analysis. The agreement in test-retest was calculated with kappa (κ). The kappa coefficient may vary from 0 to 1, where 0 is no correlation and 1 is perfect correlation. The cross-sectional validity was calculated with Spearman rank correlation coefficient (r_s) (24).

RESULTS

Translation

In synthesizing the 3 translations there was good agreement, and only small changes were needed. In the translation back to English, agreement was perfect and no further changes were necessary.

Validity Step I

All of the 11 persons in the expert group

TABLE 1
Characteristics of Patients That Took Part in the Validity Test II (n=16) or Test-Retest (n=58)

	Validity II	Test-Retest
Women/men	13/3	55/3
Median age in years, (range)	61 (22-79)	63 (25-84)
Median time since edema diagnosis, in years, (range)	7 (1-28)	10 (1-70)
Lymphedema secondary/primary /don't know	13/3/0	46/10/2
Edema of the lower limbs/upper limbs/others	9/5/2	33/25/5

responded and there were no dropouts. After analyzing the responses, some editing was done to increase clarity. One item concerning infection (cellulites), one item about compression, and one about diet was added.

Validity Step II

Sixteen patients completed the LQOLI and as well as how long it took them to answer it. All participants but two answered one or more of the additional questions (*Table 1*). The time needed to complete the LQOLI varied from 15 minutes to 2 hours and 40 minutes (median=30 minutes).

Drop outs: Three subjects dropped out of the study when they received the SLQOLI. The reason was that it was difficult to answer the SLQOLI in reference to a primary edema, or lymphedema with onset very early in life. One person was too sick from cancer to participate. Dropout individuals were younger (median=48 years) and had had their edema for a longer time (median=28 years) than the rest of study participants.

After analyzing the responses, some changes were made to the survey instrument. The most important was the increase of the time period from "the last week" to "the last month." This was because 3 patients considered 1 week too short and also that the SF-36 uses a longer time period. One instruction was added, "Concerning questions related to season, think about the whole last year." One sentence was also clarified, "If you do not relate to the concerns or problems, please note 'no effect' in the first answer column." In response to a validity question stated "Do you think that sub items 2 and 3 are relevant and possible to answer?," 7 persons answered yes, 6 did not respond, 2 considered them difficult but relevant, and 1 person said no. As a result, no answer columns were deleted and the extent of the instrument did not change.

Test-Retest and Validity Step III

Fifty-eight patients met the test-retest requirements (*Table 1*).

Drop outs: One hundred patients were asked by letter to participate and 58 completed tests 1 and 2. Thirty-seven patients did not return test 1 (median age 67 years) or completed test 1 properly; five did not respond or completed test 2 properly. For the cross-sectional comparison between the SF-36 and SLQOLI, all 63 patients that completed test 1 were included. Median for the answer time was 21 days (range=11-49 days). When adding tests 1 and 2, 21 persons stated that their past 4 weeks had been different from normal. For example "Acute pain in the back" and "Unlucky for me I am a sensitive person, my brother's unexpected death, and other psychological arduous aggravate my edema".

Result test-retest: The instrument

TABLE 2
Median and Range of the Kappa Coefficient in the 3 Sub Items of the 4 Dimensions of the Swedish Version of the Lymphedema Quality of Life Inventory

Dimension	Sub Item 1		Sub Item 2		Sub Item 3	
	median	range	median	range	median	range
Physical	0.46	0.38-0.74	0.39	0.30-0.64	0.49	0.25-0.67
Emotional	0.52	0.35-0.66	0.44	0.31-0.65	0.52	0.34-0.69
Social	0.52	0.27-0.61	0.47	0.34-0.65	0.47	0.27-0.68
Practical	0.54	0.30-0.83	0.49	0.39-0.70	0.52	0.34-0.79

TABLE 3
Percentage of Patients Answering "No Effect, Changes or Difficult" in the 3 Sub Items and 4 Dimensions of the Swedish Version of the Lymphedema Quality of Life Inventory

Dimension	Percentage answer		
	Sub item 1	Sub item 2	Sub item 3
Physical	33	39	43
Emotional	42	50	50
Social	46	46	50
Practical	44	45	49

consists of ordinal categorical data, therefore, a non-numerical kappa method was used to estimate the agreement between tests 1 and 2 (24). Each item (n=61) has 1 answer per sub item (3 sub items) and together it totaled 183 agreements.

The deviation between test 1 and 2 can vary maximum 3 steps, because every sub item has 4 answer alternatives. If the deviation is 0, the answer is the same in the two tests. There were no intervention between the two test occasions, and since the participant is supposed to have the same experience at the two tests, the deviation is equivalent to the measurement error.

The kappa coefficients in test-retest vary (range=0.25-0.83) as well as the median range in each dimension (range=0.39-0.54) (*Table 2*). All answer alternatives in all sub items and dimensions were used. The measurement error in a sub item may vary from 1 to 3. The results revealed a measurement error of at least 1 for all sub items, and varied from 3 to 29 errors.

The responses 'no effect, no changes, not difficult' were given by 33-50% of the patients (*Table 3*) which leads to the conclusion that 67% of the patients experienced effect on their quality of life within the physical dimension, 58% within the emotional dimension, 54% within the social dimension, and 56% within the practical dimension.

For the items concerning quality of life in general, the correlation is "fair" (25) and for

TABLE 4
Kappa Coefficient (κ) and Measurement Error (me)
For Test-retest of 11-point Scale in Items 1a and 1b

	n	me						κ
		0	1	2	3	4	5	
Item 1a[1]	56	19	19	10	3	5		0.21
Item 1b[2]	57	13	28	12	2	1	1	0.10

[1]Quality of life during the past month
[2]How lymphedema has affected quality of life during the past month

the lymphedema specifically the correlation is "poor" (25) (*Table 4*). In response to the item asking if this was a normal month or not, 12 persons said 'no' in test 1 and 13 persons said 'no' in test 2 (n=58). In both test 1and test 2, nine persons said it was worse or much worse.

Result validity step II: Cross-sectional validity was tested by correlation between the SF-36 and SLQOLI.

According to the definition by Munro (25), the correlation between the SF-36 and SLQOLI in this study is "moderate" for quality of life in general (mean r_s=0.65), in the practical (mean r_s=0.64), in the physical (mean r_s=0.64), and in the social dimensions (mean r_s=0.50).

DISCUSSION

The Lymphedema Quality of Life Inventory (LQOLI) is the only HRQOL instrument developed and tested in patients with different types of lymphedema. We have tested the Swedish version of LQOLI for validity and reliability and found that it can be used in clinic to describe quality of life for patients with lymphedema.

Validity

All 11 experts agreed to participate. Three participants in the patient group dropped out, with two of them finding the instrument difficult to answer because they had had lymphedema as far back as they could recall. As such, the instrument may not be applicable to patients with congenital lymphedema or lymphedema praecox with an early debut, because those patients have no "before" to relate to. Also patients that have had lymphedema for a long time may have forgotten how it was before because they may have adapted to the illness. Therefore, they might have found it difficult to answer the two last sub items, which dealt with whether changes had resulted from the lymphedema and if those changes were hard to incorporate in daily life. The first answer column about how the lymphedema affects ones quality of life may have been easier to answer on its own.

All 16 patients in the validation group filled in the SLQOLI, but not all of them answered the additional questions; two patients did not answer them at all. During the initial contact by telephone, more effort could have been put into making the patients understand the importance of answering the additional questions.

The correlation between the SF-36 and SLQOLI was moderate. In the SF-36 one has to relate to the general health, but in the SLQOLI one is asked to reflect on the health related to the lymphedema. The observed moderate correlation supports our hypothesis that the instruments correlate but also measure different aspects, leading to the

conclusion that there is a need for a specific instrument concerning lymphedema.

Test-Retest, Methods

The median age (64 years) was the same for persons who completed the test-retest and for dropouts. No other characteristics were available for assessment leaving the question as to whether the dropouts were representative for lymphedema patients from the two clinics in Sweden unanswered. However, for dropouts that stated they had no strength to fill in the SLQOLI, the median age was 10 years older (74 years). One may question whether the large numbers of items in the SLQOLI and the inclusion of three answer columns were too much for older people, though the oldest person that completed the test-retest was 84 years old.

Two subjects completed test 1 but not test 2, and many participants completed test 2 after a reminder was sent. Perhaps the written instructions could have been clearer as to the importance of completing the instrument twice. Perhaps a test of the written instructions should have been performed and improved if necessary, thereby potentially increasing the response rate as well. Another reason for non-responses could have been the extent of the instrument content.

The time between tests 1 and 2 increased from the planned 7-14 days to 11-49 days. Many circumstances that can change a patients' quality of life may occur during 49 days. What we do not know about patients with lymphedema is how much their status normally changes over time. A changed status may have impaired their quality of life and thereby the reliability of the instrument resulting in a lower kappa coefficient. Therefore, more effort should have been made to adhere to the planned time schedule.

Test-Retest, Result

The kappa coefficients in test-retest (*Table 2*) vary (range=0.25-0.83). According to Altman (24) the lowest are considered "fair" and the highest "very good." One reason that an item has "low" reliability may be that some were unclear and difficult to understand, e.g., number 15 in physical dimension "Feeling conscious of my limb all the time." Another reason may be that physical problems like pain and edema vary more than practical problems like driving a car (question number 18). Also the long response time may have interfered with physical problems that could have changed over time. If the instrument is to be used in intervention studies, the broad variability in kappa shows the need for adjustment of the instrument to exclude questions with "low" reliability.

In item 1a, the correlation was "fair" and in 1b "poor" (*Table 4*). These items have 11 answer alternatives, which can explain the relatively low correlation. Another explanation can be the long completion time between tests 1 and 2, as discussed above.

The result in *Table 3* reveals that the number of patients that responded "no effect, no changes, or not difficult" was 33-50%, which indicates that many patients had no problems with their lymphedema. Considering these participants answered no effect in the first answer column the two other columns seem unnecessary. Eliminating columns 2 and 3 would be another way to simplify the SLQOLI and thereby increase reliability.

More than 20% of the responders said that the past month was different. Mostly it was circumstances not related to the lymphedema. It may have been appropriate to exclude these patients from test-retest because their status may have changed; however, most of them reported the same reason in tests 1 and 2 so no exclusion was made.

The measurement error in a sub item may vary from 1 to 3. The results revealed a measurement error of at least 1 for all sub items, and varied from 3 to 29 errors. Therefore, this version of the SLQOLI should only be used to determine the quality of life

for the lymphedema patients at one point in time, and not to determine a change after an intervention of any kind.

The broad variability in measurement error highlights the need for adjustment of the instrument through factor analysis, keeping items with low measurement error and removing items with many errors. Such an adjustment would likely increase the reliability and make it possible to use the SLQOLI before and after an intervention. Columns 2 and 3 may be eliminated to facilitate and thereby increase reliability and the practicable use of the instrument.

CONCLUSION

Adaptation of the LQOLI to Swedish resulted in a valid instrument with moderate reliability. The Swedish version can now be used in the clinical setting to describe the quality of life in patients with lymphedema. However, the broad variability in test-retest measurement error suggests that removal of some items may facilitate completion and thereby increase sensitivity to observable changes.

ACKNOWLEDGMENT

This study was supported by grants from The Swedish Cancer Foundation.

The Swedish version of the LQOLI in Swedish and English can be found at:

HTTP://WWW.SKANE.SE/TEMPLATES/PAGE.ASPX?ID=311390

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