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Original Article

Reliability and validity of Turkish version of Lymphedema Life Impact Scale

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ABSTRACT

Objectives: In this study, we aimed to investigate the validity and reliability of the Turkish adaptation of the Lymphedema Life Impact Scale (LLIS).

Patients and methods: A total of 106 patients (103 females, 3 males; mean age 53.6±11.8 years; range, 28 to 83 years) with lymphedema who were admitted to the lymphedema outpatient clinics of our hospital between May 2016 and November 2016 were included. Reliability of the scale was assessed by internal consistency (Cronbach's alpha coefficient) and test-retest method. Validity of the scale was examined using the factor analysis and correlating the 12-Item Short-Form Health Survey (SF-12), European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30), Disabilities of Arm Shoulder and Hand (DASH), and the Lower Extremity Functional Scale (LEFS).

Results: For internal consistency, Cronbach's alpha coefficients of all subscales ranged between 0.771 and 0.865 and calculated as 0.916 as the total score. In test-retest reliability, the correlation coefficient ranged between 0.963 and 0.985 for each subscale and calculated as 0.991 for the total score. In the validity analysis, factor analysis demonstrated a probable structure of three factors which together explained 58.9% of total variance and the Turkish adaptation of the LLIS correlated with other comparison measures used in this study.

Conclusion: This study shows that the Turkish version of the LLIS is a valid and reliable scale to evaluate the quality of life in the Turkish population with lymphedema.

Keywords: Lymphedema Life Impact Scale, lymphedema, quality of life, reliability, validity.

Lymphedema is a condition characterized by the accumulation of protein-rich lymphatic fluid in the interstitial area, which develops secondary to a failure in the lymphatic system. It may be related to congenital structural abnormalities, as well as to anti-cancer treatment, surgeries, trauma, burns, and infections.[1]

Lymphedema may present with swelling, pain, limited motility in the extremities, recurrent infections, functional disabilities, and psychosocial problems. As a result, the daily activities may become difficult with impaired quality of life (QoL).[2,3] Measurement of the QoL is essential for the evaluation of the patients with chronic diseases, such as lymphedema and, hence, treatment and follow-up can be planned. The debilitating effects of lymphedema on the QoL are often evaluated using the QoL scales or cancer-specific scales; however, these scales still remain inadequate in determining lymphedema-specific problems. Therefore, the use of disease-specific scales would be more valuable for the evaluation of the effects of lymphedema.

The Lymphedema Life Impact Scale (LLIS) is a scale developed to evaluate the physical, functional, and psychosocial effects of lymphedema. Unlike other scales used for the evaluation of lymphedema, it questions the incidence of infection, which is a frequent and important complication of lymphedema. The scale consists of 18 items in three subscales: physical (8 items), psychosocial (4 items), and functional (6 items). Each item is scored from 1 to 5, with higher scores denoting

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greater severity. The validity and safety studies of the original English version have been conducted by Weiss and Daniel.[4] In the present study, we aimed to investigate the validity and reliability of the Turkish adaptation of the LLIS in patients with lymphedema.

PATIENTS AND METHODS

A total of 110 patients with lymphedema who were admitted to the lymphedema outpatient clinics of Istanbul University Cerrahpaşa Faculty of Medicine between May 2016 and November 2016 were included. Inclusion criteria were as follows: ≥18 years, having either upper or lower limb, bilateral or unilateral lymphedema, and able to read, speak, and comprehend in the Turkish language. Patients with any extremity insufficiency due to orthopedic or neurological reasons, and life-threatening or terminal illness were excluded. Two patients were also excluded due to diffuse metastatic disease, one was due to brachial plexus involvement, and one due to a frozen shoulder. Finally, 106 patients (103 females, 3 males; mean age 53.6±11.8 years; range, 28 to 83 years) completed the study.

Age, sex, occupation, height, weight, additional diseases, history of cancer, duration of lymphedema, swelling in the affected extremity, tightness, heaviness, stiffness, pain, and numbness were questioned. The location, etiology, and stage of lymphedema were recorded. Circumference measurements of the affected and ipsilateral extremity were made. The foci of measurement were determined as the metacarpophalangeal joint, the wrist, the 10 cm distal and the proximal parts of the elbow in the upper extremity, and metatarsophalangeal joint, the ankle, the 10 cm distal and the proximal parts of the knee in the lower extremity. The differences between the extremities were recorded in cm.

Permission of the authors of the LLIS scales was obtained for translation into Turkish. As the first step, the scale was translated into Turkish independently by two researchers who had specialty in medicine and one translator who had advanced experience in the English language. The translations included differences in some words, although they referred the same meaning. Therefore, a synthesis of the most appropriate matches in the Turkish and those fitting best in English was made. The final adaptation was performed via comparison of the original English scale to the Turkish scale. For pilot testing, cognitive debriefing was performed with 10 patients. During a cognitive debriefing interview, participants were asked to identify any words that were difficult to understand and explain in their own words the meaning of each sentence in the questionnaire. This procedure evaluated the feedback about how clearly the questions of the scale was understood and how they could be better expressed. The final version of the scale was constructed based on these feedbacks.

All patients included in the study filled out the LLIS scale under the guidance of a supervisor in the hospital setting. In order to provide a base for the validity study of the scale, additional scales were performed such as the 12-Item Short-Form Health Survey (SF-12)[5] and European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30)[6] for those who had a history of cancer, Disabilities of the Arm, Shoulder and Hand (DASH)[7] for those with upper extremity lymphedema, and Lower Extremity Functional Scale (LEFS)[8] for those with lower extremity lymphedema. To determine the reliability of the scale using the repeat-test method, the scale form was repeated two weeks after the first application on 28 patients. The patients who performed this second scale were selected among those with no change in the situation of the diseases between the two evaluations.

A written informed consent was obtained from each participant. The study protocol was approved by Istanbul University Cerrahpasa Faculty of Medicine Ethics Committee. The study was conducted in accordance with the principles of the Declaration of Helsinki.

Statistical analysis

Statistical analysis was performed using the IBM SSPS version 20.0 software (IBM Corp., Armonk, NY, USA). For the reliability analysis, the internal consistency and the test-retest reliability were measured. To evaluate the internal consistency, the Cronbach's alpha values were calculated for the total scale and for the subscales. A Cronbach's alpha coefficient of >0.7 was accepted as internally consistent. The Cronbach's alpha coefficient may be obtained, when there are no missing data. Accordingly, Question 14, which was on the occupational life of the patients, was excluded since only 18 of the 106 patients were working and was not answered by the remaining patients. Test-retest reliability was evaluated using the intraclass correlation coefficient (ICC) together with a 95% confidence interval (CI) using two-way mixed models.

Factor analysis was applied to examine the construct validity. The principal component analysis

and varimax rotation were used. The preliminary tests for factor analysis included the Kaiser-Meyer-Olkin (KMO) test (for the adequacy of the sample size) and Bartlett's test (for sphericity). For the evaluation of the relationship of the scale with lymphedema, comparisons between the groups with and without the symptoms frequently observed in lymphedema were made using the Mann-Whitney U test. The relationship between the scale and difference in the circumference measures of the extremities was analyzed using the Kruskal-Wallis test. Correlation analyses were performed using the results of the scale with the results of SF-12, EORTC QLQ-C30, DASH, LEFS scales. The Spearman coefficient of correlation was used for the correlation analyses of the scales. A coefficient of correlation of >0.5 was accepted as strong correlation, a correlation of between 0.3 and 0.5 was accepted as moderate correlation and a correlation of below 0.3 was accepted as a weak correlation.[9] A *p* value of <0.05 was considered statistically significant.

RESULTS

Lymphedema was present in the upper extremity in 74.5% of the patients and in the lower extremity in 25.5% of the patients. In the upper extremity lymphedema group, 3.8% of the patients had primary lymphedema and 96.2% had secondary lymphedema. Among the patients with upper extremity lymphedema, the etiology of secondary lymphedema included breast cancer in 75 patients, and lymphoma in one patient. The demographic and clinical characteristics of the patients are presented in Table 1.

For internal consistency, Cronbach's alpha coefficients of all subscales ranged between 0.771 and 0.865 and calculated as 0.916 as the total score (Table 2).

In test-retest reliability, the correlation coefficient ranged between 0.963-0.985 for each subscale and calculated as 0.991 for total score (Table 3).

The Kaiser-Meyer-Olkin (KMO) of sampling adequacy was 0.882, and the Bartlett´s test of sphericity was significant (p<0.001), confirming the appropriateness of using factor analysis on the data. Three factor structure represented 58.9% of the total variance. The Eigenvalue was found to be 7.318 for factor 1, 1.453 for factor 2, and 1.244 for factor 3. Communalities of items were 0.4 to 0.758. When factor loadings of the items were evaluated in appropriate factors to the original scale, loading values of the items 1-8 in factor 3 were 0.309 to 0.748, the items 9-12 in factor 2 were 0.571 to 0.818, and the items 13-18 in factor 1 were 0.214 to 0.770.

The mean scores in the total of LLIS scale and in the subscales were significantly higher in the

Table 1. Demographic and clinical characteristics of patients

	Upper extremity group (n=79)				Lower extremity group (n=27)			
	n	%	Median	Min-Max	n	%	Median	Min-Max
Age (year)			55	35-83			52	28-82
Gender								
Female	77	97.5			26	96.3		
Male	2	2.5			1	3.7		
Body mass index			29	17-53			32	24-55
Employed (yes)	13	16.5			5	18.5		
Etiology								
Primary lymphedema	3	3.8			9	33.3		
Secondary lymphedema	76	96.2			18	66.6		
Breast cancer	75	95						
Other cancers	1w	1.3			7	26		
Non-cancer surgery					6	22.2		
Obesity					3	11.1		
Trauma					1	3.7		
Chronic venous insufficiency					1	3.7		
Lymphedema stage								
Stage 1	10	12.7			1	3.7		
Stage 2	69	87.3			22	81.5		
Stage 3					4	14.8		
Duration of lymphedema (month)			24	1-396			54	1-384

Min: Minimum; Max: Maximum.

Table 2. Cronbach's alpha

	Cronbach's alpha
Physical	0.865
Psychosocial	0.808
Functional	0.771
Total	0.916

Table 3. Test-retest reliability (n=28)

	ICC	%95 CI	*p*
Physical	0.985	0.968-0.993	<0.001
Psychosocial	0.966	0.915-0.985	<0.001
Functional	0.963	0.914-0.983	<0.001
Total	0.991	0.963-0.997	<0.001

ICC: Intraclass correlation coefficient; CI: Confidence interval.

group with each symptom of swelling, tightness, heaviness, stiffness and pain in the symptomatic group, compared to asymptomatic group (p<0.001). The mean physical and functional subscale and total scores of the scale in the group with numbness were significantly higher compared to the group without numbness (p=0.022, p=0.002, p=0.01), and the mean psychosocial subscale score was higher as well, although not significant (p=0.205).

According to the comparison of circumferential measures of the affected extremity with the healthy extremity, the patients were divided into three groups as mild (less than 3 cm), moderate (3 to 5 cm) and severe (more than 5 cm).[10] The relationship between the extremity groups and scale scores are shown in Table 4.

The total scores observed in the patients with upper extremity lymphedema demonstrated a strong correlation with the SF-12 physical (PCS-12) and mental (MCS-12) components. Physical and functional subscales demonstrated a strong correlation with PCS-12 and moderate correlation with MCS-12. Psychosocial subscale demonstrated a moderate correlation with PCS-12 and strong correlation with MCS-12. The scale and all subscales demonstrated a strong correlation with DASH. The scale and all subscales demonstrated a strong correlation with the functional component of EORTC QLQ-C30 in patients with cancer. The total and physical and functional subscales of the scale demonstrated a strong correlation with the EORTC QLQ-C30 symptom component, whereas the psychosocial subscale demonstrated a moderate correlation (Table 5).

The total scale score and all subscale scores demonstrated a strong correlation with PCS-12 and MCS-12 in those with lower extremity lymphedema.

Table 4. The relationship between the extremity groups and scale scores

	Physical		Psychosocial		Functional		Total	
	Median	Min-Max	Median	Min-Max	Median	Min-Max	Median	Min-Max
Mild (n=44)	13	9-32	5	4-16	7	5-20	24.5	19-60
Moderate (n=32)	20.5	12-29	8.5	4-20	11	6-18	38.5	22-57
Severe (n=30)	23	13-32	11	4-19	12	5-23	49	24-70
Mild-moderate (*p*)	0.006		0.013		0.031		0.009	
Mild-severe (*p*)	<0.001		<0.001		<0.001		<0.001	
Moderate-severe (*p*)	0.283		0.179		0.423		0.126	

Min: Minimum; Max: Maximum.

Table 5. The relationship between the scale and SF-12, DASH and EORTC QLQ-C30 in the upper extremity lymphedema group

Upper extremity (n=79)	PCS-12	MCS-12	DASH	EORTC functional (n=76)	EORTC symptom (n=76)
	p	*p*	*p*	*p*	*p*
Physical	-0.501**	-0.477**	0.724**	0.615**	0.562**
Psychosocial	-0.468**	-0.642**	0.580**	0.616**	0.496**
Functional	-0.703**	-0.453**	0.764**	0.690**	0.636**
Total	-0.611**	-0.569**	0.785**	0.723**	0.637**

* p<0.05; ** p<0.01; SF-12: Short-Form Health Survey; DASH: Disabilities of the Arm, Shoulder and Hand; EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; PCS-12: Physical; MCS-12: Mental.

Table 6. The relationship between the scale and SF-12, LEFS and EORTC QLQ-C30 in the lower extremity lymphedema group

Lower extremity (n=79)	PCS-12	MCS-12	LEFS	EORTC functional (n=7)	EORTC symptom (n=7)
	p	*p*	*p*	*p*	*p*
Physical	-0.672**	-0.542**	-0.531**	0.214	0.487
Psychosocial	-0.513**	-0.638**	-0.331	0.000	0.560
Functional	-0.741**	-0.577**	-0.673**	0.487	0.527
Total	-0.734**	-0.614**	-0.560**	0.393	0.577

* p<0.05; ** p<0.01; SF-12: Short-Form Health Survey; LEFS: Lower Extremity Functional Scale; EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; PCS-12: Physical; MCS-12: Mental.

The total score, physical and functional subscales of the scale demonstrated a strong correlation with LEFS. No correlation was found between the psychosocial subscale and LEFS. No correlation was found between the scale and subscales and EORTC QLQ-C30 in those with lower extremity lymphedema (Table 6).

DISCUSSION

In the present study, we attempted to translate the original version of the LLIS into Turkish for Turkish-speaking patients with lymphedema and to evaluate its validity and reliability. Our study results show that the Turkish version of LLIS is a reliable, internally consistent, and valid questionnaire in Turkish patients with lymphedema.

In our study, the Cronbach's alpha value was >0.7 for the complete scale and each subscale. Furthermore, the total alpha value of the scale, which was 0.916 (>0.9), indicated a perfect internal consistency of the scale. Question 14, which questions the limitations in the professional life, was answered by 17% of the patients, since only a small rate of the patients had an occupation. No missing data should be present to calculate the Cronbach's alpha, which is used to evaluate the internal consistency of the scale. Similar problems were encountered during the validity and safety studies of the original scale due to the patients being non-workers or retired, and only 40 of 71 patients could be evaluated to analyze the Cronbach's alpha value in the total scale or in the functional subscale due to the missing data in this question. The authors mentioned that the question on the professional life could be reconstructed in the future version of the scale, since it led to a poor performance during the analysis.[4] Thus, this question was excluded in our study, since the rate of the patients to answer this question would be very low.

For the test-retest reliability of the scale, the statistical difference between the measurements at two different time points should be compared. Thus, the ICC should be determined. An ICC value of >0.75 indicates a good, and a value of >0.9 indicates a perfect reliability. In our study, all values of the scale and subscales were >0.9 showing a perfect reliability.

For the evaluation of the differential ability of the scale of patients with and without symptoms specific to lymphedema, we questioned the presence of the symptoms frequently observed in lymphedema such as swelling in the affected extremity, tightness, heaviness, stiffness, pain and numbness. Accordingly, 93.4% of the patients had swelling, 73.6% had tightness, 70.8% had a feeling of heaviness, 64.2% had stiffness, 59.4% had pain, and 40.6% had numbness. Similarly, in a study investigating 24 symptoms, all patients had swelling, 71.4% had tightness, 71.4% had a feeling of heaviness, 42.9% had stiffness, 45.2% had pain, and 45.2% had numbness.[11] In the present study, we observed that the mean scores in the LLIS and its subscales were higher in patients with lymphedema-related symptoms.

To date, many studies have investigated the relationship between lymphedema-related swelling and QoL. It was demonstrated in a study including patients with breast cancer that psychosocial incompliance and psychological morbidity were higher in the group with lymphedema compared to those without lymphedema, which was not related to the size of the swelling.[12] In the study of Pain et al.[13] which included patients with breast cancer-related lymphedema, no relationship was found between the excess volume and manual skills or physical functions. In the study of Keeley et al.,[14] no correlation was observed between the extremity volume and QoL among those with lower extremity lymphedema. Since it is difficult to provide volumetric measurement materials, circumferential measurement is commonly used to evaluate lymphedema-related swelling.[15] In our study, we classified our patients according to their circumferential measurements to provide more valuable data for clinical practice.

We found a significant difference between the mild and moderate lymphedema groups in all subscales of the scale and the total score. Similarly, a significant difference was observed between all mild and severe lymphedema groups in all mean scores. When the moderate and severe lymphedema groups were compared, all mean scores were higher in the severe lymphedema group compared to the moderate group, although it did not reach statistical significance.

Factor analysis is used to evaluate construct validity. Considering the results of the KMO and Bartlett's test, the data were considered suitable for factor analysis. Factor analysis aimed to fix the number of components to three as in the original version. Three factor structures represented 58.9% of the total variance. Communalities of all items were ≥0.4. The factor loadings of all items except question 16 were found to be >0.3 in related factors. However, as the number of sample increases, the low load values may become significant; therefore, Question 16 is preserved in the related subscale.

For the evaluation of the structural validity, the outcomes of the newly developed scale are compared to those of the previous scales, and the relationship between them is analyzed. In our study, a significant correlation was found between the LLIS and its subscales with all other surveys in patients with upper extremity lymphedema. In those with lower extremity lymphedema, a significant correlation was observed between the scale and its subscales and PCS-12 and MCS-12. The total score of the scale, and the physical and functional subscales demonstrated a significant correlation with LEFS, whereas the psychosocial subscales did not demonstrate a significant correlation. This may be explained by the questions in the LEFS survey not containing any questions regarding psychosocial problems. In the lower extremity lymphedema group, we found no correlation between the scale and EORTC QLQ-C30 in seven patients with a history of cancer, who underwent the EORTC QLQ-C30 survey. Since the number of patients with a history of cancer in the lower extremity lymphedema group was low in our study, we believe that suggesting no correlation between the scale and the EORTC QLQ-C30 survey by the data obtained would not be proper.

The main limitation of the present study is the low number of male participants. However, considering the pathophysiology of lymphedema and clinical findings, there is no reason to suggest a difference in the lymphedema-related problems between sexes. Another limitation of our study is the exclusion of the question on the limitations in the professional lives of the patients, since it was answered by very few patients. It was also mentioned in the study where the original version of the scale was evaluated that this question would be reconstructed, since it was answered by a low rate of the patients and it showed a poor performance.

In conclusion, this study shows that the Turkish version of the LLIS is a valid and reliable scale to evaluate the QoL in the Turkish population with lymphedema.

Declaration of conflicting interests

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