



Original Article

Lymphoedema functioning, disability and health questionnaire Turkish version: translation, cross-cultural adaptation and validation

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Abstract. [Purpose] The purpose of this study was to adapt the Lymphoedema Functioning, Disability and Health Questionnaire into the Turkish language, and to evaluate the psychometric properties of the Turkish version in patients with breast cancer-related lymphedema. [Subjects and Methods] After the translation, inter-rater and test-retest reliability were assessed between patients and physiotherapists using the intra-class correlation coefficient. Thirty patients with breast cancer-related lymphedema were asked to fill out the Turkish version of the Lymphoedema Functioning, Disability and Health Questionnaire two times, one week apart. Internal consistency was tested using Cronbach's alpha, and the test-retest reliability was assessed by calculating the intra-class correlation coefficient. Construct validity was investigated by comparing the results of the Lymphoedema Functioning, Disability and Health and Short Form-36 questionnaires. [Results] The test-retest reliability and inter-tester reliability of the Lymphoedema Functioning, Disability and Health Questionnaire total score, physical function score, mental function score, household activities score, mobility activities score, life and social activities score were excellent. [Conclusion] The Turkish version of the Lymphoedema Functioning, Disability and Health Questionnaire was found to be valid and reliable for patients with breast cancer related lymphedema.

Key words: Lymphoedema Functioning Disability and Health Questionnaire, Turkish, Validation

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INTRODUCTION

Breast cancer is the most prevalent cancer amongst women but it has the highest survival rate of all cancers¹⁾. Approximately 25% of breast cancer patients develop lymphedema following breast cancer treatment²⁾. Breast cancer treatments may damage the lymph vessels and nodes, resulting in impaired lymph transport capacity and the accumulation of protein-rich interstitial fluid in the torso or upper extremity³⁾.

Lymphedema causes limb and shoulder pain, heaviness, tightness, and decreased range of motion. Anxiety, depression, and emotional distress are more common among patients with breast cancer-related lymphedema (BCRL)^{4, 5)}. This condition may lead to difficulty with activities of daily living ranging from overhead reaching, lifting, carrying objects, to caring for family and returning to work. After breast cancer treatment, women who develop lymphedema have greater restrictions in activities of daily living, and report poorer quality of life than women without lymphedema^{6, 7)}.

Quality of life instruments are used to describe and evaluate functioning in clinical practice. Because it is a complex term that involves different contexts, the World Health Organization (WHO) developed the International Classification of Functioning, Disability and Health (ICF)⁸⁾. Since quality of life questionnaires and the ICF represent two different perspectives regarding functionality and health, they are used simultaneously in clinical practice⁹⁾. Carvalho et al.¹⁰⁾ studied patients who

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had breast cancer surgery and reported that long-term follow-up is necessary to better define the disability of this population.

The Lymphoedema Functioning, Disability and Health questionnaire (Lymph-ICF) assesses impairments in function, activity limitations, and participation restrictions related to lymphedema developed after axillary dissection for breast cancer, and it is based on the terminology of the ICF¹¹).

A study showed that the original Lymph-ICF had high internal consistency, excellent test-retest reliability, good convergent validity with the Short Form-36 (SF-36) questionnaire, and good responsiveness¹²).

The aims of this study were to cross-culturally adapt the Lymph-ICF for Turkish-speaking patients, and to determine the clinimetric properties of its reliability, criterion validity, internal consistency, and measurement error for patients with BCRL.

SUBJECTS AND METHODS

The Lymph-ICF was translated into Turkish and culturally adapted in accordance with the method recommended by Beaton et al¹²). A total of 30 female patients were recruited for the study. The study group consisted of patients diagnosed with lymphedema with complaints after breast cancer surgery. The inclusion criteria were as follows: unilateral mild or moderate lymphedema following breast cancer surgery lasting for at least three months, and an age between 25 and 75 years, and the ability to reply to visual or verbal instructions. A difference in circumference of up to 2 cm indicated mild lymphedema, and a difference of 2–5 cm was classified as moderate lymphedema. The exclusion criteria were as follows: lymphangitis or musculoskeletal problems. The patients' demographic and clinical characteristics were recorded. The affected side of the patients was 15 (50%) for the right upper extremity and 15 (50%) for the left upper extremity. The clinical assessment revealed 7 (23.3%) patients had mild lymphedema and 23 (76.7%) patients had moderate lymphedema.

The Lymph-ICF questionnaire is composed of 29 questions. Each question is answered using a visual analog scale (VAS) ranging from 0 to 100 mm. The anchors for the impairments in function (e.g. "Does your arm hurt?") are "not at all" and "very much," and those for the activity limitations and participation restrictions (e.g. "Are you able to carry heavy weights?") are "very well" and "not at all." The Lymph-ICF has 5 domains: physical function, mental function, household activities, mobility activities, and life and social activities. The total score of the Lymph-ICF is equal to the sum of the scores of the questions divided by the total number of answered questions. The Lymph-ICF takes about 5 minutes to complete.

The 36 item short-form (SF-36) was constructed to survey health status in the Medical Outcomes Study. The SF-36 was designed for use in clinical practice and research, health policy evaluations, and general population surveys. The SF-36 includes one multi-item scale that assesses eight health concepts: 1) limitations of physical activities because of health problems; 2) limitations of social activities because of physical or emotional problems; 3) limitations of usual role activities because of physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations of usual role activities because of emotional problems; 7) vitality (energy and fatigue); and 8) general health perceptions. The survey was constructed for self-administration by persons 14 years of age or older, and for administration by a trained interviewer in person or by telephone. This study was approved by the institutional ethical board of Medipol University and was conducted in accordance with the Declaration of Helsinki. All subjects read and signed an informed consent form.

The English version of the Lymph-ICF was adapted for Turkish use according to the established guidelines for cross-cultural adaptation of self-reported questionnaires. The guideline has 5 steps: (1) translation, (2) synthesis, (3) back translation, (4) evaluation by a team of experts, and (5) pretests. In step one, the English version of the Lymph-ICF was translated into Turkish by two independent native Turkish speakers (two physiotherapists) who were fluent in English. Both translators were informed of the procedure. In step two, both translations were assembled by two translators and a team of experts. In step three, the Turkish translation of the Lymph-ICF was translated back into English by two persons, who were bilingual native English speakers and did not receive any information about the Lymph-ICF. In step four, all the translations were reviewed by an expert committee consisting of the forward and back translators, one physiotherapist specialized in lymphedema disorders and one other physician. Consensus was achieved on semantic, idiomatic, experiential and conceptual features and the prefinal version of the Turkish Lymph-ICF was consolidated. In step five, the prefinal versions of Turkish Lymph-ICF were tested using ten patients with lymphedema to determine the accuracy of the wording and understanding of the test items at an outpatient physiotherapy department. The interviewer (one physiotherapist) defined and recorded any problems occurring during the filling out of the prefinal Turkish Lymph-ICF questionnaire. After consideration of these issues, a final Turkish version of the Turkish Lymph-ICF was established. The questions were understood by all of the patients and there were no ambiguities. Therefore, the Turkish versions of the questionnaires did not need any changes.

The reliability and validity of the final Turkish versions of the Turkish Lymph-ICF was tested using 30 patients with lymphedema. All patients completed the Turkish version of the Lymph-ICF and the Turkish version of the SF-36 in a first examination under supervision of one of the authors (AK) at the outpatient physiotherapy department. On the second visit 7 days later, the patients completed the same questionnaires again under supervision of the same assessor (AK) and another assessor (ZH) to determine the test-retest and inter-tester reliability, respectively.

The Statistical Package for Social Science (SPSS) software version 21.0 (SPSS Inc., Chicago, IL, USA) was used for statistical analysis. The normality of the distribution was assessed using the Kolmogorov-Smirnov test, which found they were normally distributed. For categorical variables, the data are presented as descriptive statistics (means and standard

deviations, frequencies and percentages) were reported.

The reliability of the Lymph-ICF scale was assessed using the reproducibility (test-retest reliability) of scores, and the internal consistency of the scale. Test-retest and inter-tester reliability were determined using the interclass correlation coefficient ($ICC_{(2,1)}$) and the $ICC_{(2,k)}$, respectively. An ICC value of >0.70 indicates that an instrument is reliable. The internal consistency of the Lymph-ICF was assessed using Cronbach's alpha. The internal consistency is considered acceptable when Cronbach's $\alpha > 0.7$.

The validity of the construct was analyzed by examining correlations between the Lymph-ICF scores and the SF-36 scores. Pearson correlation coefficients were used to evaluate construct validity because Lymph-ICF and SF-36 scores were continuous variables and were normally distributed. Correlation coefficients were rated as follows: strong correlation >0.6 ; moderate ≤ 0.6 and >0.3 ; and poor ≤ 0.3 . Statistical significance was accepted for values of $p \leq 0.05$.

RESULTS

The questionnaires were given to 30 patients and all of the patients completed the questionnaires in full. The mean age of the patients was 53.8 ± 5.8 years and their mean lymphedema complaint duration was 18.2 ± 7.7 months (Table 1).

Investigation of the test-retest stability over the 7-day interval found that the difference between the two measurements was not statistically significant ($p > 0.05$). The results of the reliability analyses and the mean scores of the subscales are presented in Table 2. The test-retest reliability (ICC range, 0.80–0.99, Cronbach's alpha range, 0.89–0.99) and inter-tester reliability (ICC range, 0.73–0.99, Cronbach's alpha range, 0.85–0.99) of the Lymph-ICF total score, physical function score, mental function score, household activities score, mobility activities score, and the life and social activities score were excellent.

Table 3 shows the results of the validity analyses. There were significant correlations between the Lymph-ICF total score, physical function score, mental function score, household activities score, mobility activities score, life and social activities score and the SF-36 subscales (Physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health) (range, 0.03–0.49). The correlations between the Lymph-ICF physical function and SF-36 physical functioning total ($r = -0.49$ $p = 0.005$), and the Lymph-ICF physical function and SF-36 social functioning ($r = -0.463$ $p = 0.010$), were strong. The correlations between the Lymph-ICF mobility activities and SF-36 general health ($r = -0.41$ $p = 0.020$), the Lymph-ICF life and social activities and SF-36 bodily pain ($r = -0.39$ $p = 0.032$), and the Lymph-ICF life and social activities and SF-36 mental health ($r = -0.37$ $p = 0.044$) were moderate.

DISCUSSION

The present study, demonstrated that the Lymph-ICF is a valid and reliable tool for assessing the impairments in function, activity limitations, and participation restrictions of patients with BCRL patients. The original Dutch and English versions of the Lymph-ICF have been found to be valid and reliable instruments for women with arm lymphedema. Since all of the patients found the questions understandable, it wasn't necessary to change any item. The test-retest indicated the subscales had adequate to excellent reliability and the Lymph-ICF questionnaire as a whole had very good reliability. In the literature, test-retest reliabilities of the total score and of the physical function and household activities scores were reported as very strong ($ICC > 0.90$), those of the mental function and mobility activity scores strong ($ICC > 0.75$), and that of the life and social activities score moderate ($ICC = 0.65$) for the original version of the Lymph-ICF¹¹. In our study, the test-retest reliabilities of the physical function, mental function, and life and social activity scores were very strong ($ICC > 0.90$), and those of the Lymph-ICF total, household activities and mobility activities were strong ($ICC > 0.75$), the same as for the original version of the Lymph-ICF. The ICC results in our study were higher than those reported for the original version of the Lymph-ICF¹¹. This may be because the first and second Lymph-ICF were conducted at different times. The time interval between repeated measurements is an important factor in the determination of test-retest reliability. The reliability tends to be higher when an interval of 7 days or less is used, because short test-retest intervals can elicit similar responses¹². Therefore, 7 days was chosen for the retest assessment interval to decrease the possibility of participants' remembering the questions. It is our opinion that the conditions of the BCRL patients wouldn't be expected to change over this period¹³.

In this study, the well-established questionnaire SF-36 was chosen because it is a widely used generic health related quality of life instrument both in Turkey and worldwide, and it has with demonstrated validity and reliability for cancer patients¹⁴.

For the concurrent validity, Pearson correlation coefficients of the subscales of the Lymph-ICF and SF-36 were computed. The physical functioning domain of the Lymph-ICF showed strong correlations with the physical and social functioning domains of the SF-36; the mobility activities domain of the Lymph-ICF showed a moderate correlation with the general health domain of the SF-36; the social activities domain of the Lymph-ICF showed a moderate correlation with the body pain domain of the SF-36.

The correlations between the SF-36 and scores of specific instruments are typically weak. This confirms that the SF-36 measures additional aspects of physical health and provides more comprehensive, but less specific, information about a patient's overall health than condition-specific questionnaires. The Lymph-ICF showed stronger correlations with was more strongly related to concurrent measures of physical and social functions than to concurrent measures of general health. In the literature, Klernas et al. used SF-36 and Lymphedema Quality of Life Inventory (LyQLI) in their validation study¹⁵. They

Table 1. Demographic and clinical characteristics of the patients

Characteristics	Mean \pm SD, n	Range
Age (years)	53.8 \pm 5.8	(39–6)
BMI (kg/m ²)	30.4 \pm 4.1	(24.3–39.8)
Mean duration of lymphedema (month)	18.2 \pm 7.7	(6–3)
Mean duration of operation (month)	28.5 \pm 9.6	(10–4)
Severity lymphedema (patients)		
Mild	7 (% 23.3)	
Moderate	23 (% 76.7)	
Dominant side (R/L)	26/4	
Affected side (R/L)	15/15	

BMI: body mass index, R: right, L: left

Table 2. Test-retest and inter-tester reliability of the Turkish versions of the Lymph-ICF

Self-reported outcome measurements	Assessor I	Assessor I	Assessor II	Assessor I	Assessor I	Cronbach's alpha	Cronbach's alpha
	First assessment	Second assessment		First-Second assesment	First-Assessor II		
Lymph-ICF total	46.53 \pm 19.11	46.90 \pm 17.94	46.53 \pm 17.56	0.90	0.99	0.98	0.99
Physical function (Heavy, stiff, swollen, lost strength, tingle, hurt, tensed skin)	43.33 \pm 24.59	43.53 \pm 24.39	43.43 \pm 23.59	0.99	0.99	0.99	0.99
Mental function (Feel sad, feel discouraged, lack of self confidence, feel stressed)	41.90 \pm 30.53	42.73 \pm 30.10	43.06 \pm 29.67	0.99	0.99	0.99	0.99
Household activities (Clean, cook, iron, garden)	54.13 \pm 38.26	52.00 \pm 28.12	53.36 \pm 30.28	0.80	0.89	0.73	0.85
Mobility activities (Tasks with elevated arm, lift heavy objects, sleep on affected side, work on computer, sunbathe, drive a car, walk more than 2 km, cycle)	57.16 \pm 35.65	53.46 \pm 26.83	55.00 \pm 27.60	0.85	0.92	0.83	0.90
Life and social activities (Go on vacation, perform hobbies, practice sports, wear clothes of choice, do a job, do social activities)	47.13 \pm 25.95	48.53 \pm 27.75	47.60 \pm 25.58	0.98	0.99	0.99	0.99

ICC: intraclass correlation coefficient

Table 3. Construct validity: correlation analysis of the Turkish versions of the Lymph-ICF and SF-36

Lymph ICF	SF-36 Domain				
	Physical function	Mental function	Household activities	Mobility activities	Life and social activities
Physical functioning	-0.498**	-0.075	0.026	-0.136	-0.088
Role-physical	-0.139	0.071	0.056	0.182	0.337
Bodily pain	-0.266	-0.076	0.066	-0.223	-0.393*
General health	-0.185	-0.349	-0.357	-0.416*	-0.323
Vitality	-0.150	-0.355	-0.184	-0.287	-0.203
Social functioning	-0.463**	-0.087	-0.030	-0.208	-0.262
Role-emotional	-0.274	0.056	0.077	0.071	-0.156
Mental health	-0.030	-0.215	-0.133	-0.171	-0.371*

*Moderate correlation, **Strongest correlation

demonstrated there were correlations between the scores of the domains of the LyQLI and the physical and mental scores of the SF-36, as also found by our present study. As expected, SF-36 and the Lymph-ICF have similar items due to the SF-36 being a generic quality of life scale.

The internal consistency analysis using Cronbach's alpha showed all the questions to be within the recommended range of values (0.70–0.95)¹⁶⁾. The Cronbach alpha values of the present study are higher than 0.70 and similar to the values reported by Viehoff et al.¹⁷⁾ who tested the ULL-27. Devoogdt et al. reported Cronbach's alpha values of 0.72–0.92 which are similar to the values of our present study.

Limitations of this study include the lack of comparison between patients with BCRL and healthy women. In the recent literature there was no other report of validation and cultural adaptation of Lymph-ICF to other languages.

In conclusion, based on the results of this study, the Turkish version of the Lymph-ICF is reliable and may be applicable in clinical research and practice for BCRL patients.

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