

Quality of Life Questionnaires in Breast Cancer-Related Lymphedema Patients: Review of the Literature

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Abstract

Purpose: Lymphedema of the arm is one of the most common and underestimated side effects of breast cancer treatment. It is known to negatively affect the quality of life (QoL) in breast cancer survivors. However, there are multiple questionnaires used to measure QoL in lymphedema patients. The current study aimed to determine the most complete and accurate questionnaire.

Methods: A systematic literature search in Cochrane Library database CENTRAL, MEDLINE, and EMBASE was conducted in August 2016 by two independent researchers. The strategy used for the search was: (“Lymphedema”[Mesh]) AND (“Quality of life”[Mesh])). All QoL questionnaires for patients with breast cancer-related lymphedema (BCRL) were included. An overview of the assessed QoL domains and arm symptom-specific questions was made, to assess the most complete and accurate questionnaire.

Results: A total of 142 studies were identified, of which 49 met the inclusion criteria and 15 different questionnaires were extracted. The Lymphedema Quality of Life Inventory (LyQLI), assesses all QoL domains, except for the possibility of wearing the clothes of choice, and assess all specific arm symptoms. The Lymphedema Functioning, Disability, and Health (Lymph-ICF) Questionnaire assesses all QoL domains, except for sexual functioning, and does assess all specific arm symptoms.

Conclusion: According to the results obtained, the LyQLI and Lymph-ICF questionnaires were the two most complete and accurate questionnaires to assess QoL in patients with BCRL, because these questionnaires assess the largest number of QoL domains and specific arm symptoms.

Keywords: breast cancer, lymphedema, quality of life, questionnaire

Introduction

BREAST CANCER IS THE most frequent cancer affecting women all over the world and its incidence has doubled during the last decades.^{1,2} Due to early detection and improved treatment there is an increased number of long-term breast cancer survivors.^{1–3} Therefore, there is an increased focus on the quality of life (QoL) and Patient Reported Outcome Measures (PROMs).^{4,5} Besides, the overall QoL in these long-term breast cancer survivors is important to measure the impact of specific treatments on the different QoL domains.^{6–8}

Lymphedema of the arm is considered one of the most distressing and underestimated side effects of breast cancer treatment.^{9–13} Breast cancer-related lymphedema (BCRL) is caused

by an acquired interruption of the axillary lymphatic system after locoregional treatment such as radiotherapy and/or lymph node dissection.^{14–17} Previous studies showed that the incidence of lymphedema of the arm ranged between 8.4% and 21.4% after breast cancer treatment, with an estimate incidence of 16.6%.¹⁸

Lymphedema is known to have a significant impact on the physical, psychological, and social health of patients.^{18–21} To measure the actual impact of BCRL on QoL, a good questionnaire is mandatory. However, there is no consensus about the best questionnaire to measure QoL in these patients with BCRL. Several different questionnaires have been used for patients with BCRL in previous studies.^{22–35} A recent review assessed the quality of four QoL questionnaires in patients with BCRL.³⁶ However, more different questionnaires than four

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have been used in all other previous studies.^{22–35} Furthermore, the previous review compares the validity of the questionnaires, but the amount of different aspects of QoL was not taken in account. In the present study a literature review was performed to provide an overview of the different questionnaires, to assess the most complete and accurate one, not only based on validity but also on the amount of different aspects of QoL. The different subdomains included in the questionnaires were analyzed to target the impact of BCRL with more accuracy.

Methods

This systematic review was conducted according to the PRISMA guidelines.³⁷

Data sources

A systematic literature search in MEDLINE, EMBASE, and the Cochrane Library database CENTRAL was conducted in March 2017 to identify all questionnaires reporting on QoL in BCRL patients. The search was performed using predefined search terms: (“Breast cancer-related lymphedema”[Mesh]) AND (“Quality of life”[Mesh])). The reference lists of included articles were hand searched to supplement the literature search to ensure that no relevant studies were missed by the search strategy.

Selection process

Eligibility assessment of the articles was performed in a standardized manner by two independent reviewers. The title

and abstract of all retrieved hits were screened and reviewed individually to identify all relevant articles reporting on QoL in patients with lymphedema of the arm. No restrictions for language, publication date, or publication type were applied. All variations of questionnaires measuring QoL were identified based on the full-text versions of the articles. Disagreements between both reviewers were resolved by consensus.

Data extraction

A data extraction sheet was developed containing information about the questionnaires. For each of these questionnaires, the following variables were gathered: full name and abbreviation of the questionnaire, validity (Cronbach’s alpha coefficient), type of answer, and the assessed QoL domains (physical function, mental function, daily activities, hobbies and job, mobility, social activities, and sexual function). Using this data extraction sheet, a selection of questionnaires was made, based on the number of QoL domains assessed. Questionnaires which assessed all or all except one QoL domains were selected. For the selected questionnaires another data extraction sheet was developed, containing information about the arm symptom-specific questions, which were assessed in the questionnaires. Specific arm symptoms were: pain, heaviness, swelling/tightness, loss of strength, tingles/burning/pins, skin problems, possibility to elevate the arm, movement difficulties of the arm, and problems in wearing the clothes of choice.

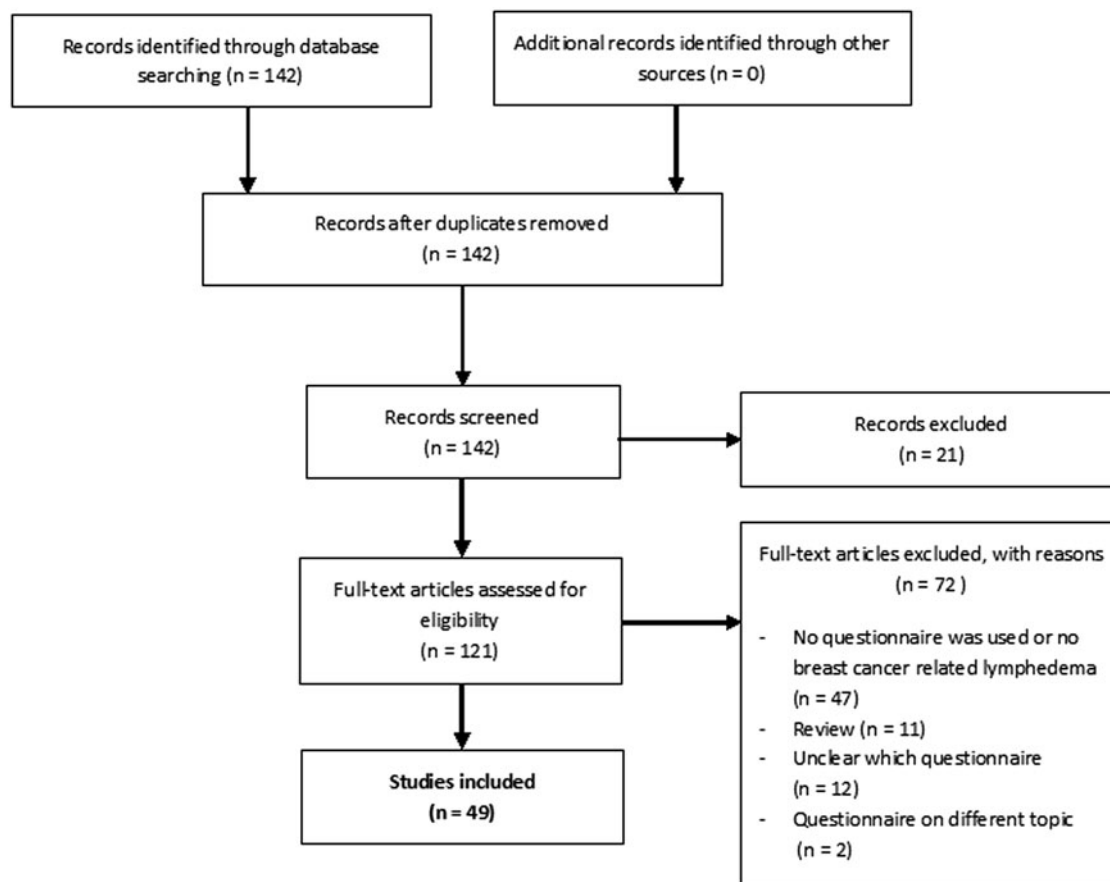


FIG. 1. Flow diagram of the literature search according to PRISMA statement.

Results

Study selection

The literature search identified a total number of 142 studies. After selection, using the criteria described in Figure 1, 49 studies were included. In these 49 studies, 15 different questionnaires were used.

Questionnaire characteristics

The 15 identified questionnaires were subdivided in three categories:

Group I: General health questionnaires; this group consisted of six questionnaires.

Group II: Cancer-specific questionnaires; this group consisted of three questionnaires.

Group III: Lymphedema-specific questionnaires; this group consisted of six questionnaires.

All of the assessed questionnaires were validated previously (Table 1).

In group I, one out of six questionnaires used a combination of visual analogue scale (VAS) score and categories. The

rest of the questionnaires used categories. All the questionnaires reported on mental function. Only one questionnaire reported on hobbies and jobs. Four questionnaires reported on physical function and daily activities. In addition, only one questionnaire included questions on mobility, two on social activity, and one on sexual function. The DASH questionnaire was the only questionnaire in this group which assessed all QoL domains.

In group II, the EORTC QLQ-C30 is a cancer-specific questionnaire, which is commonly used in combination with the EORTC QLQ-BR23 questionnaire. Altogether, these questionnaires provide a complete breast cancer-specific questionnaire, assessing all QoL domains. All questionnaires in this group used a categorical score.

In group III, only the Lymphedema Functioning, Disability and Health (Lymph-ICF) questionnaire used a VAS score. The rest of the questionnaires used categories. Two out of six questionnaires assessed all QoL domains, the other four assessed all QoL domains, except for sexual function (Table 2).

Eight of the included questionnaires assessed all or all except one QoL domains; these questionnaires were selected for further analyses on assessment of arm symptom-specific questionnaires. Four of them assessed all QoL domains, the

TABLE 1. OVERVIEW OF ASSESSED QUESTIONNAIRES, WITH VALIDATION

Questionnaire (abbreviation)	Questionnaire (full name)	No. of studies	Validation Author Year	Consistency validity (n)	Cronbach's α coefficients
Group I					
SF-36	Short Form 36	12	Brazier et al. 1992	1582	0.73–0.96
DASH	Disabilities of Arm, Shoulder, and Hand	4	Dias et al. 2008	100	0.98
HADS	Hospital Anxiety and Depression Scale	1	Bjelland et al. 2002	Review	0.67–0.93
McGill Pain score	McGill Pain score	1	Melzack 1987	16	0.74–1.00
MYMOP	Measure Yourself Medical Outcome Profile	1	Barbosa Lima et al. 2016	74	0.38–0.62
PANAS	Positive and Negative Affect Schedule	1	Watson et al. 1988	Unknown	0.86–0.90
Group II					
EORTC QLQ-C30	Quality of Life Questionnaire Core-30	12	Tan et al. 2014	170	0.85
EORTC QLQ-BR23	Quality of Life Questionnaire Breast-23	11	Sprangers et al. 1996	170	0.57–0.89
FACT-B	Functional Assessment of Cancer Therapy Breast Cancer	11	Coster et al. 2001	279	0.62–0.88
Group III					
Lymph-ICF	Lymphedema Functioning, Disability, and Health	5	Devoogdt et al. 2011	60	>0.70
ULL 27	Upper Limb Lymphedema 27	3	Launois et al. 2002	301	0.82–0.93
LSIDS-A	Lymphedema Symptom and Intensity Survey-Arm	1	Ridner et al. 2015	236	0.93–0.94
LyQLI	Lymphedema Quality of Life Inventory	2	Klernäs et al. 2015	126	0.87–0.92
PBI-L	Patient Benefit Index—Lymphedema	1	Blome et al. 2014	65	0.80–1.00
LYMQOL	Quality of Life measure for limb lymphedema	1	Keeley et al. 2010	209	0.83–0.88

TABLE 2. OVERVIEW OF ASSESSED QUALITY OF LIFE DOMAINS IN THE DIFFERENT QUESTIONNAIRES

Questionnaire	Answer type	Physical function	Mental function	Daily activities	Hobbies and job	Mobility	Social activities	Sexual function
Group I								
SF-36	Categories	x	x	x	—	—	x	—
DASH	Categories	x	x	x	x	x	x	x
HADS	Categories	—	x	—	—	—	—	—
McGill Pain Score	Categories-VAS	x	x	x	—	—	—	—
MYMOP	Categories	x	x	x	—	—	—	—
PANAS	Categories	—	x	—	—	—	—	—
Group II								
EORTC QLQ-C30	Categories	x	x	x	x	x	x	—
EORTC QLQ-BR23	Categories	x	x	—	—	—	—	x
FACT-B	Categories	x	x	—	x	—	x	x
Group III								
Lymph ICF	VAS	x	x	x	x	x	x	—
ULL 27	Categories	x	x	x	x	x	x	—
LSIDS	Categories	x	x	x	x	x	x	x
LyQLI	Categories	x	x	x	x	x	x	x
PBI-L	Categories	x	x	x	x	x	x	—
LYMQOL	Categories	x	x	x	x	x	x	—

VAS, visual analogue scale.

other four assessed all QoL, except for sexual function. One of the selected questionnaires was in Group I, one in Group II, and six were in Group III. Table 3 shows an overview of the assessed arm symptom-specific questions for each selected questionnaire.

The questionnaires from group I and II assessed only four out of nine arm symptoms. The questionnaires from group III assessed between six and nine arm symptoms. The Lymph-ICF was the only questionnaire, which assessed all nine arm symptoms. The Lymphedema Quality of Life Inventory (LyQLI) assessed all arm symptoms, except for the possibility to wear the clothes of choice.

Discussion

A large number of questionnaires are currently used to assess QoL in BCRL patients.^{22–35} The objective of the present study was to provide an overview of the different questionnaires, to assess the most complete and accurate one to measure QoL.

Previous studies showed that lymphedema of the arm in breast cancer survivors did not influence global QoL. However, there was a major impact on many specific symptoms such as fatigue and arm symptoms.^{6–8} This suggests that more specific PROMs are needed to measure QoL. In this context, to measure the impact of lymphedema on QoL it is not only important to assess global QoL and the different QoL domains, but also to assess all specific arm symptoms.

The Lymph-ICF and the LyQLI assessed most QoL items, the different QoL domains, and the specific arm symptoms. In the Lymph-ICF all QoL domains, except for sexual function are assessed and all arm symptom-specific questions are assessed. In the LyQLI, all QoL domains are assessed and all arm-specific questions, except for the possibility of wearing all clothes of choice are assessed.

An important difference between the Lymph-ICF and the LyQLI is the answer type. The Lymph-ICF uses VAS, whereas the LyQLI uses categorical answers. A VAS is commonly used to rate various subjective experiences, and therefore it is often used in QoL measurements. Potential

TABLE 3. OVERVIEW OF ARM SYMPTOM-SPECIFIC QUESTIONS IN COMPLETE QUESTIONNAIRES ON QUALITY OF LIFE DOMAINS

	Pain	Swelling/ Heaviness	tightness	Loss of strength	Tingle/ burning/pins	Skin problems	Elevation of the arm	Movement difficulties	Wearing clothes of choice
Group I									
DASH	x	—	—	x	x	—	—	x	—
Group II									
C30 + BR23	x	x	—	—	—	—	x	x	—
Group III									
Lymph-ICF	x	x	x	x	x	x	x	x	x
ULL-27	—	x	x	x	x	x	x	x	—
LSIDS	x	x	x	—	x	—	x	x	—
LyQLI	x	x	x	x	x	x	x	x	—
PBI-L	x	—	x	—	—	x	—	x	x
LYMQOL	x	x	x	x	x	—	—	x	x

advantages of these scales are the wide score range and high sensitivity. An important disadvantage is that they have a lower completion rate than other rating scales.³⁸

In the present study the EORTC QLQ-C30 and QLQ-BR23 questionnaires were assessed together, because this combination is commonly used for breast cancer survivors. This questionnaire combination contains all QoL domains. However, only four out of nine arm symptom-specific questions were assessed in this combined questionnaire. Therefore, this questionnaire combination might not be accurate enough to measure QoL in patients with BCRL.

Another questionnaire which seemed to fulfill the demands after the first analysis was the DASH. The DASH also contains all QoL domains. However, similar to the QLQ-C30/QLQ-B23, only four out of nine arm symptom-specific questions were assessed.

Both the DASH and the QLQ-C30/QLQ-BR23 did not contain questions about swelling of the arm. However, it should be mentioned that often before an increase in volume is measurable, patients experience symptoms such as tenderness and numbness of the arm.³⁹

Conclusion

In conclusion, the Lymph-ICF and LyQLI questionnaires seem to be the two most complete and accurate questionnaires to assess QoL in patients. Based on our results, one of these two questionnaires should be used in research and clinical practice concerning QoL in BCRL patients.

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Author Disclosure Statement

No competing financial interests exist.

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