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RESEARCH

Danish translation and cultural adaptation of the LYMPH-Q upper extremity lymphedema worry and impact on work scales

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Abstract

Background Breast cancer-related lymphedema (BCRL) significantly affects health-related quality of life (HR-QOL). The LYMPH-Q Upper Extremity (UE) Module is a patient-reported outcome measure (PROM) designed to assess HRQL in individuals with BCRL. Recently, two new scales, Lymphedema Worry and Impact on Work, were developed to expand the module's comprehensiveness. This study aimed to perform a translation and cultural adaptation of these scales for use in Denmark.

Methods The translation process followed best-practice guidelines from the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and the World Health Organization (WHO). The methodology included a forward and back translation, an expert panel review, and cognitive debriefing interviews with patients to ensure linguistic and cultural equivalence.

Results The forward translations revealed eight minor discrepancies in terminology, which were resolved through discussion. The back translation identified one item requiring refinement to align with the original English meaning. The expert panel participants suggested modifications regarding three items to enhance cultural relevance. Cognitive debriefing interviews with patients ($n = 10$) confirmed that the translated items were clear and comprehensible. The final proof reading led to minor modifications which resulted in the final Danish version of the LYMPH-Q Lymphedema Worry and Impact on Work scales.

Conclusions The rigorous translation and cultural adaptation process resulted in a conceptually equivalent Danish version of the LYMPH-Q UE module Lymphedema Worry and Impact on Work scales. These scales will provide valuable insight into the occupational and psychological burdens of BCRL among Danish patients.

Level of evidence Not ratable.

Keywords Patient-reported outcome measure · PROM · Health-related quality of life · HRQL · Breast cancer · Lymphedema · Translation · Cultural adaptation

Introduction

Breast cancer is one of the most common malignancies among women worldwide, with a significant proportion of women developing breast cancer-related lymphedema (BCRL) following treatment [1]. BCRL leads to swelling, discomfort, and functional limitations, which negatively impact daily life and psychosocial well-being [2].

Objective assessments of outcome, such as limb volume measurements, indocyanine green lymphangiography and bioimpedance spectroscopy, are commonly used to evaluate BCRL. However, these measures do not capture the full patient experience, including pain, distress, and activity

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limitations. Patient-reported outcome measures (PROMs) offer a more comprehensive assessment by incorporating the patient's perspective on disease burden and treatment outcomes [3].

The LYMPH-Q Upper Extremity (UE) Module was developed to assess health-related quality of life (HRQL) in women with BCRL due to limitations of existing PROMs [4, 5]. Originally, the module consisted of six scales covering symptoms, function, appearance, psychological impact, information, and arm sleeve use. To further improve comprehensiveness, two additional scales—lymphedema worry and impact on work —were developed to assess the occupational and emotional challenges faced by patients with BCRL [6]. This study aimed to translate and culturally adapt these new scales into Danish to ensure their applicability in Denmark, in order to add them to the existing Danish version of the LYMPH-Q UE module [7].

Methods

The translation and adaptation of the LYMPH-Q UE module Lymphedema Worry and Impact on Work scales followed established best-practice guidelines from the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and the World Health Organization (WHO). The project was approved by the XXX (journal nr. 22/45963). We have previously applied the combination of these guidelines for PROM translation in our institution [7–11].

The process involved six key steps:

1. **Preparation**: Approval was obtained from relevant authorities. Permission for translation was granted by the LYMPH-Q UE module developers.
2. **Forward translation**: Two independent translators, fluent in both English and Danish (native), produced forward translations. The forward translations were compared, and discrepancies were discussed to generate a harmonized Danish version 1.
3. **Back translation**: A professional translator, blinded to the original English version, translated the harmonized Danish version 1 to English. The back translation was compared to the original in collaboration with the LYMPH-Q UE module developers. Discrepancies and inconsistencies were identified and solved, leading to the Danish version 2.
4. **Expert panel review**: An expert panel consisting of clinicians with experience in lymphedema treatment such as a plastic surgeon and a physiotherapeutic lymphedema specialist, the professional translators, and a patient-representative reviewed the Danish version 2 to ensure conceptual equivalence, cultural relevance, and applicability in the Danish clinical setting. Their feedback was incorporated into the Danish version 3.
5. **Cognitive debriefing interviews**: A sample of Danish patients with BCRL ($n=10$) participated in cognitive interviews to assess clarity, comprehensibility, and relevance. Any problematic items were revised, leading to Danish version 4.
6. **Proofreading and Finalization**: The final version was proofread by two independent experts to identify and remove errors.

Results

Ten female patients with breast cancer-related lymphedema participated in the cognitive debriefing interviews. Participants were aged 35–84 years, with most classified as ISL stage 2 ($n=9$). The median time since breast cancer treatment was 6.5 years (range: 3–37), and 5 years since lymphedema diagnosis (range: 2–16). Most patients used compression garments, and several received manual lymphatic drainage or physiotherapy. Detailed characteristics are presented in Table 1.

The forward translation process revealed eight minor discrepancies in terminology, which were resolved through

Table 1 Patient characteristics from the cognitive interviews

Age (years)	Number, *n*
35–44	1
45–59	5
60+	4
Lymphedema stage (ISL*)	Number, n
0	1
2	9
Level of Education	Number, n
Ph.D.	1
Master's degree	2
Medium-Cycle Higher Education	3
Vocational Education and Training	3
Upper Secondary Education	1
Time since breast cancer treatment (years) Median (range)	6.5 (3–37)
Time since lymphedema diagnosis (years) Median (range)	5.0 (2–16)
Current Treatment	Number, n
Compression sleeve	7
Compression glove	5
Compression vest	3
Night Compression sleeve	2
Night compression glove	1
Physiotherapy	2
Cardio and resistance training	1
Manual lymphatic drainage	3
None	3

*ISL (International Society of Lymphology)

discussion. An example was the translation of the word "worse," which was translated into two different words with the same meaning. After a thorough discussion, the translators reached agreement on which word provided a more precise and contextually accurate description. This word alone accounted for four of the eight discrepancies identified, as it was used multiple times throughout the scales.

The back translation identified one item requiring modification to align with the original English meaning. This discrepancy was discussed with the developers of the LYMPH-Q UE module to ensure a conceptually equivalent Danish version.

The expert panel suggested revisions to three items for enhanced cultural adaptation. The first revision concerned the item "I felt self-conscious of my arm at work" (item 2 in the Impact on Work scale). The panel discussed whether the term "self-conscious" carried a negative connotation in Danish, and there was consensus that it did. Therefore, the phrase was changed to "jeg var meget opmærksom på min arm på arbejde" ("I was very aware of my arm at work"). This translation was more aligned with the English word "aware" instead of "self-conscious" to better capture the intended meaning without having a negative connotation. The second revision addressed the phrase "to care for" in the item "I needed breaks to care for my arm (e.g., stretch, rest)" (item 4 in the Impact on Work scale). The panel noted that a precise Danish equivalent was lacking and attempts to translate the phrase directly made the sentence awkward. To maintain clarity, the decision was made to omit the phrase "to care for" entirely and instead emphasize the need for breaks, specifying in parentheses that it could include activities like stretching or resting. The third revision involved item 8 in the Lymphedema Worry scale: "I worried when I was not seen regularly by someone for lymphedema treatment." The panel decided to change "when" to "if" to avoid implying that irregular treatment was the norm. The revised wording, "I worried *if* I did not get lymphedema treatment regularly." made the item sound less deterministic and more contextually appropriate.

Cognitive debriefing interviews conducted with 10 patients with BCRL confirmed that the Danish version was relevant and comprehensible. The cognitive interviews did not identify any major issues requiring changes or further interviews, however, some comments and suggestions from participants were noted and addressed to further improve clarity and cultural adaptation.

Three patients noted that some work-related questions appeared repetitive, particularly questions 5, 6, and 7, which were perceived as similar in content and challenging to differentiate. Additionally, one patient noted that question 14 was similar to question 7. These redundancies were noted and will be taken into account by the developers when the two new scales are field-tested and shortened based on the psychometric analysis.

Overall, the cognitive debriefing interviews confirmed that the final Danish version was well-received, and that the questionnaire had both clarity and cultural relevance.

The final Danish version of the LYMPH-Q UE module's Lymphedema Worry and Impact on Work scales was proofread by two clinicians, with only minor grammatical adjustments made. This final study resulted in the translated and linguistically validated version of the Lymphedema Worry and Impact on Work scales that are ready to field-test in Danish patients.

Discussion

Rigorous translation and cultural adaptation of PROMs is essential to ensure that they retain their validity and relevance across different languages and cultures. The six-step methodology employed in this study, which combines ISPOR and WHO guidelines, proved effective in producing a high-quality Danish translation.

During concept elicitation interviews of the LYMPH-Q UE module, it became evident that certain key concerns of patients with BCRL were not fully addressed by existing scales [6]. Through detailed qualitative interviews and focus groups, patients highlighted two major challenges: the emotional burden of living with BCRL and its impact on their ability to work. These insights led to the creation of two additional scales: Lymphedema Worry and Impact on Work.

The lymphedema worry scale was developed in response to patients' anxiety and uncertainty about their condition. Many participants expressed concerns about the progression of lymphedema, worsening symptoms, and long-term management. These fears had impact on their overall well-being, making it crucial to include a scale that could capture the psychological impact of living with lymphedema.

Similarly, the Impact on Work scale was introduced after patients reported difficulties in performing work-related tasks, such as manual labor, lifting, and typing. The physical limitations imposed by arm swelling and discomfort often led to reduced work efficiency, changes in job roles, or even an inability to work altogether. Incorporating this scale into the LYMPH-Q UE module provides a means to ensure occupational consequences of lymphedema can be systematically assessed.

To develop these scales, researchers conducted concept elicitation interviews to gather initial insights, followed by cognitive debriefing interviews to refine the wording and structure. Additionally, focus groups with experts and patients helped ensure the scales were clinically relevant, comprehensive, and easy to understand. Finally, a second

round of pilot testing confirmed their validity and usefulness in capturing the real-world impact of lymphedema on patients' lives.

Cross-cultural adaptation of PROMs like the LYMPH-Q is fundamental to ensure comparable, high-quality data across populations. In line with other translations, including the recent Italian version by Cogliandro et al. [12], our work provides a culturally adapted version of the newly developed scales. These tools address key patient concerns about anxiety, uncertainty, and work ability after breast cancer, and they can support both patient education and shared decision-making in lymphedema management.

The LYMPH-Q Upper Extremity Module is already being used internationally to measure health-related quality of life in patients with breast cancer-related lymphedema [13–15], which supports the rationale for translating these additional scales. Including the Lymphedema Worry and Impact on Work scales further enhances the questionnaire's ability to capture critical patient experiences and strengthens its utility in both clinical practice and research.

Cross-cultural adaptation of PROMs like the LYMPH-Q is fundamental to ensure high-quality, comparable data across populations, and supports shared decision-making and patient education. By translating and culturally adapting these two new scales, the LYMPH-Q UE module becomes more comprehensive, addressing both mental health challenges and work-related consequences of lymphedema. These additions will allow clinicians and researchers to better monitor patient-reported outcomes, tailor interventions, and ultimately improve quality of care for breast cancer survivors in Denmark [3, 4].

Future research should focus on psychometric validation of the translated scales, including reliability testing and responsiveness analysis in the Danish patient population.

Conclusions

A rigorous translation and cultural adaptation process resulted in a Danish version of the LYMPH-Q UE module Lymphedema Worry and Impact on Work scales. These new scales will provide valuable insights into the occupational and emotional challenges of BCRL in Denmark.

Author contributions All authors contributed according to the journal guidelines.

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Data availability No datasets were generated or analysed during the current study.

Declarations

Human ethics and consent to participate According to Danish legislation, questionnaires to not require approval from the National Ethics Committee. The study was approved by the regional ethics committee (No. 24/22826).

Consent to participate (Danish) All participants gave their written informed consent to participate in this study.
Jeg bekræfter hermed, at jeg har fået nok oplysninger om projektet til at vurdere min deltagelse. Jeg har fået skriftlig og mundtlig information om projektets indhold, herunder hvilke typer af oplysninger, der indsamles om mig, samt hvad disse oplysninger skal bruges til og hvorledes de behandles.
Jeg ved, at det er frivilligt at deltage, og at jeg altid kan trække mit samtykke tilbage uden at miste mine nuværende eller fremtidige rettigheder til behandling.
Jeg har fået en kopi af denne erklæring samt af den skriftlige information om projektet til eget brug.
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Competing interests The authors declare no competing interests.

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