



Discussion: “Development and Psychometric Validation of a Patient-Reported Outcome Measure for Arm Lymphedema: LYMPH-Q Upper Extremity Module”

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The present study aims to expand on the authors' extensive experience with the development of patient-reported outcome measures (PROMs) for evaluation of patients suffering from breast cancer-related lymphedema (BCRL).¹ Although 14 lymphedema-specific PROMs have been developed to measure upper extremity lymphedema outcomes from the patient perspective, a systematic literature review identified that 13 of these were developed with limited input from patients, which is crucial to ensure content validity, and all had low to moderate reliability and validity.² The LYMPH-Q Upper Extremity Module introduced here was developed using a psychometric approach with consideration of the patient's perception of the degree of debilitation and response to treatment, as well as input from 15 patients and 12 medical professionals, followed by validation with 364 patients in the USA and 2858 Danish patients.

A validated PROM is unquestionably vital to the care of patients suffering from lymphedema, which plagues a significant portion of patients undergoing treatment for breast cancer.^{3–6} In particular, it is critical to have an objective measure to determine the efficacy of treatment, as many insurance providers continue to deny coverage for lymphedema surgery on the basis of a lack of objective evidence confirming its efficacy. High-volume lymphedema surgeons are able to achieve successful, reproducible outcomes using either lymphovenous bypass

(LVB) or vascularized lymph node transfer (VLNT) approaches, and the combined approach has now been demonstrated to achieve superior outcomes.^{7–11} Data confirming improvements in patients' quality of life following surgery are critical to demonstrate the benefit of lymphedema surgery and justify the need for coverage of these operations. The finding in this study that wearing a compression sleeve within the past year was associated with worse outcomes on all six scales is an important justification for lymphedema surgery, which is the only way that this can be achieved. With the validated LYMPH-Q based on input from patients and medical providers and implementation with 3222 patients, increased utilization of this PROM will provide further confirmation of the efficacy of lymphedema surgery and a common assessment tool with comparable scoring that can help to facilitate international research into these treatments.

While the LYMPH-Q is undoubtedly a useful tool that will have tremendous potential, it was based on input from 15 patients, which is somewhat limited and consisted predominantly of Caucasian patients. As the patients were volunteers from a larger cohort of 58 patients, there could be issues of selection bias from the input of the 15 patients whose experience with lymphedema and degree of debilitation is clearly subjective and may be exaggerated compared with others, or perhaps underestimated. Issues such as the degree of dependency on complete decongestive therapy (CDT), number of infections, whether the patient was hospitalized, hand dominance, and employment and occupation can all affect patient responses, which may not be fully addressed with a limited sample size. This similarly affects the validation of the LYMPH-Q using 16 patients with lymphedema. As the authors acknowledge, of the 3222 participants in the field-test sample, the majority were Danish (89%) and White (87%), which limits

applicability, and further validation studies should include a more ethnically diverse sample recruited from other countries. Conversion of the LYMPH-Q to another language in this study is a valuable component that demonstrates the potential for translation to other languages, which will undoubtedly be necessary to maximize the exposure of the PROM to non-English-speaking patients once validated.

With the growing popularity of lymphedema surgery, including prophylactic lymphedema surgery, the need for a validated PROM is increasingly critical, and it should be a standard component for any institution or practice performing high-volume lymphedema surgery.¹² However, whether or not the LYMPH-Q will replace or prove superior to other currently available PROM remains to be determined, in particular as the LYMPH-Q was designed specifically for BCRL; the reliability of this tool therefore needs to be compared with tools currently in use, including the Lymphedema Life Impact Scale (LLIS) and the Lymphedema Quality of Life (LYMQOL) questionnaire. There is an important need for a similar tool to be developed to evaluate lower extremity lymphedema.

The authors should be commended for their important contribution to the management and care of patients suffering from BCRL, as well as outcomes research, in providing a PROM with strong content and construct validity.

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REFERENCES

1. Klassen A, Tsangaris E, Poulsen L, et al. Development and psychometric validation of a patient-reported outcome measure for arm lymphedema: LYMPH-Q upper extremity module. *Ann Surg Oncol*. 2021. <https://doi.org/10.1245/s10434-021-09887-y>.
2. Beelen LM, van Dishoeck AM, Tsangaris E, et al. Patient-reported outcome measures in lymphedema: a systematic review and COSMIN analysis. *Ann Surg Oncol*. 2021;28(3):1656–68.
3. Armer JM, Ballman KV, McCall L, et al. Factors associated with lymphedema in women with node-positive breast cancer treated with neoadjuvant chemotherapy and axillary dissection. *JAMA Surg*. 2019;154(9):800–9.
4. Naoum GE, Roberts S, Brunelle CL, et al. Quantifying the impact of axillary surgery and nodal irradiation on breast cancer-related lymphedema and local tumor control: long-term results from a prospective screening trial. *J Clin Oncol*. 2020;38(29):3430–8.
5. Byun HK, Chang JS, Im SH, et al. Risk of lymphedema following contemporary treatment for breast cancer: an analysis of 7617 consecutive patients from a multidisciplinary perspective. *Ann Surg*. 2019. <https://doi.org/10.1097/SLA.0000000000003491>.
6. Nguyen TT, Hoskin TL, Habermann EB, Cheville AL, Boughey JC. Breast cancer-related lymphedema risk is related to multidisciplinary treatment and not surgery alone: results from a large cohort study. *Ann Surg Oncol*. 2017;24(10):2972–80.
7. Schaverien MV, Coroneos CJ. Surgical treatment of lymphedema. *Plast Reconstr Surg*. 2019;144(3):738–58.
8. Schaverien MV, Chang EI. Combined deep inferior epigastric artery perforator flap with vascularized groin lymph node transplant for treatment of breast cancer-related lymphedema. *Gland Surg*. 2021;10(1):460–8.
9. Yang JC, Wu SC, Lin WC, Chiang MH, Chiang PL, Hsieh CH. Supermicrosurgical lymphaticovenous anastomosis as alternative treatment option for moderate-to-severe lower limb lymphedema. *J Am Coll Surg*. 2020;230(2):216–27.
10. Chang EI, Ibrahim A, Liu J, et al. Optimizing quality of life for patients with breast cancer-related lymphedema: a prospective study combining DIEP flap breast reconstruction and lymphedema surgery. *Plast Reconstr Surg*. 2020;145(4):676e–85e.
11. Beederman M, Garza RM, Agarwal S, Chang DW. Outcomes for physiologic microsurgical treatment of secondary lymphedema involving the extremity. *Ann Surg*. 2020. <https://doi.org/10.1097/SLA.0000000000004457>.
12. Ozmen T, Lazaro M, Zhou Y, Vinyard A, Avisar E. Evaluation of simplified lymphatic microsurgical preventing healing approach (S-LYMPHA) for the prevention of breast cancer-related clinical lymphedema after axillary lymph node dissection. *Ann Surg*. 2019;270(6):1156–60.

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