A Core Outcome Set for Breast Cancer-Related Lymphedema: A Delphi Consensus Study

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Introduction: There are numerous Outcome Measures (OMs) that Certified Lymphedema Therapists (CLTs) may use with Breast Cancer Survivors (BCS) with Breast Cancer-Related Lymphedema (BCRL). A consensus-based Core Outcome Set (COS) narrows extensive choices of OMs. A COS diminishes selective reporting on conditions, inconsistency in clinical use, and variability of reporting across interdisciplinary medical fields that manage and/or research BCRL. Aims: The aims are to 1) develop a consensus-based COS for BCRL; and 2) identify consensus-based OM instruments used for the COS.

Method: This ongoing 2-phase Delphi study includes two electronic surveys. A heterogeneous group of professionals managing BCRL are recruited. A 2-wave Phase-1 recruitment protocol was launched with purposive sampling followed by snowball sampling, with the goal of enrolling 30-60 participant experts in BCRL management and research in Wave 1. Wave 2 has been launched to recruit Lymphology Association of North America (LANA) members. Consensus was defined a priori as a minimum of 70% agreement for all domains and subdomains. We expect analysis completion for the two waves of the Phase-1 survey by 4/15/23 and will subsequently disseminate the Phase-2 survey. A third survey to resolve discrepancies will be disseminated if consensus is not reached.

Results: Data from 39 completed Wave-1 surveys are currently undergoing analysis. The sample included Massage Therapist (n = 1, 2.6%), Occupational Therapist (n =8, 20.5%), Physical Therapist (n = 14, 35.9%), Physical Therapist Assistant (n = 2, 5.1%), Physician (n = 8, 20.5%), and Registered Nurse (n = 1, 2.6%). A majority reported a Clinical Doctorate degree (n = 14, 36%), followed by Master's (n = 8, 21%), Bachelors (n = 7, 18%), and other Academic degrees (n = 5, 12.8%). Respondents worked a mean of 25.2 years (range = 5 – 47 years). Years as a CLT (n = 29, 74%) had an average of 15.7 years, with 61% (n = 23) being LANA-credentialed. Years of experience with BCRL ranged from 10 years in the 25th percentile, 15 years in the 50th percentile, and 22 years in the 75th percentile. Primary works settings were hospital-based outpatient clinics (n = 20, 51%) and non-hospital-based outpatient clinics (n = 10, 26%).

Conclusions: Data are currently under analysis with results for both waves of the Phase-1 survey expected to be ready for dissemination on 5/1/23. We anticipate study findings will support clarification and collaboration in understanding and applying a COS among professionals in BCRL.