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# A Review of Health Related Quality of Life Assessments for Patients with Lymphedema

Bonnie C. Blair  
*University of Puget Sound*

Gina M. Dellino  
*University of Puget Sound*

Jennifer E. Thomas  
*University of Puget Sound*

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A Review of Health Related Quality of Life Assessments for  
Patients with Lymphedema

May 2017

This evidence project, submitted by  
Bonnie C. Blair, OTS, Gina M. Dellino, OTS, and Jennifer E. Thomas, OTS  
has been approved and accepted  
in partial fulfillment of the requirements for the degree of  
Master of Science in Occupational Therapy from the University of Puget Sound.

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Project Chairperson: Tatiana Kaminsky, PhD, OTR/L

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OT635/636 Instructors: George Tomlin, PhD, OTR/L, FAOTA; Renee Watling, PhD, OTR/L, FAOTA

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Director, Occupational Therapy Program: Yvonne Swinth, PhD, OTR/L, FAOTA

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Dean of Graduate Studies: Sunil Kukreja, PhD

*Key words:* Lymphedema, Quality of Life, Psychometric, Lymphedema Life Impact Scale (LLIS), Disabilities of the Arm, Shoulder, and Hand (DASH)

**Abstract**

In collaboration with Heidi Shaffer, one of the occupational therapists on staff at the MultiCare lymphedema clinic in Gig Harbor, Washington, we sought to answer the question “Which patient-reported outcome assessments are most valid and reliable in measuring health-related quality of life (HRQoL) in patients with lymphedema?” We conducted a systematic literature review to answer this question. In reviewing selected databases, 19 articles were chosen to appraise the evidence supporting psychometric properties and clinical utility of 10 HRQoL assessments used for patients with lymphedema. The Disability of the Arm, Shoulder and Hand (DASH) and Lymphedema Life Impact Scale (LLIS) assessments demonstrated stronger evidence for test-retest reliability, internal consistency, and clinical utility for use in a lymphedema practice setting in the U.S. than other assessments.

The next step was to bring the findings back to Heidi and her colleagues to answer questions they had about using recommended assessments to generate G-codes for Medicare reporting and to explore strategies that could be used to implement these recommended assessments within MultiCare’s electronic medical record (EMR) system. We provided an in-service on our findings for MultiCare’s lymphedema therapists, at which time we distributed laminated calculation cards for converting DASH scores to G-code modifiers and obtained feedback through a satisfaction survey. In addition, we met with the Director of Physical Medicine and Rehabilitation at MultiCare, Sherri Olsen, to determine the best process for embedding the LLIS and the DASH into their EMR and identify future research needs. Additional steps will include follow up on the progress and outcomes of embedding the assessments into the EMR and further research to address changes in the literature, HRQoL assessments for other diagnostic populations, and determining the efficacy and benefits of prehab treatments.

**Executive Summary**

This year-long review effort began by asking the question, “Which functional outcome measures used by lymphedema therapists are best for determining G-codes?” In order to meet the needs of our collaborating clinician, Heidi Shaffer from the MultiCare lymphedema clinic in Gig Harbor, our research question was changed to, “Which patient-reported outcome assessments are most valid and reliable in measuring health-related quality of life in patients with lymphedema?” Currently, HRQoL measures specific to patients with lymphedema are lacking psychometric rigor. These instruments are particularly critical following a recent mandate by Medicare to produce G-codes, which report function-related outcomes. Our aim with this literature review was to provide local lymphedema therapists with recommended HRQoL assessments that could be used within the facility’s electronic medical record (EMR) system to generate Medicare G-codes.

We conducted a systematic literature review to appraise the evidence supporting the psychometric properties and clinical utility of 10 HRQoL assessments used for patients with lymphedema. To determine which assessments to include in our review, we first identified HRQoL assessments commonly used in lymphedema research. Next, we reviewed selected databases and chose 19 articles that met our inclusion criteria (i.e. the study was peer-reviewed, analyzed one or more of the selected assessments) and exclusion criteria (i.e. published prior to 1980, study population did not include patients with cancer and/or lymphedema, and not available in English). Each article was categorized using American Occupational Therapy Association (AOTA) levels of evidence and the research pyramid. All articles were considered and reviewed by five individuals for inclusion in this review.

After critically appraising the articles, we determined that the DASH and the LLIS assessments demonstrated the strongest evidence for test-retest reliability, internal consistency, and clinical utility for use in a lymphedema practice setting in the U.S. We concluded there was strong evidence to recommend the DASH and modest evidence to recommend the LLIS for use with patients with lymphedema. Specifically, this review supports the use of the DASH for patients with lymphedema when lymphedema is secondary to breast cancer. For patients with lymphedema not secondary to breast cancer, the LLIS was found to be the most appropriate assessment at this time. Practitioners should evaluate the characteristics of each assessment against a client's specific presentation (e.g. comorbidities, upper limb versus lower limb, etc.) to select the

most appropriate assessment tool. Use of psychometrically sound assessments arms practitioners with objective data to quantify function and progress of treatment. This demonstrates the effects of intervention to third-party payers for purposes of reimbursement. In addition, such assessments provide cohesion across therapists and settings and communicate intervention outcomes with a variety of disciplines along the continuum of care.

To translate our findings into clinical practice, we conducted an in-service presentation to MultiCare lymphedema therapists in Tacoma, WA., at which time we distributed laminated calculation cards for converting DASH scores to G-code modifiers. At the conclusion of our presentation, we obtained feedback through a satisfaction survey. Based on results from the survey, we concluded that we adequately informed clinicians about psychometric properties of lymphedema HRQoL assessments. We also concluded that some clinicians did not find the G-code modifier card useful, and that they were unlikely to begin using the DASH if they were not already. In addition, we met with the Director of Physical Medicine and Rehabilitation at MultiCare, Sherri Olsen, to determine the best process for embedding the LLIS and the DASH into their EMR system. Next steps will include follow up on the progress and outcomes of embedding the assessments into their EMR. Future research is needed to address changes in the literature, to identify HRQoL assessments for other diagnostic populations, and to determine the efficacy and benefits of prehab treatments.

**Focused Question:**

Which patient-reported outcome assessments are most valid and reliable in measuring health-related quality of life (HRQoL) in patients with lymphedema?

**Collaborating Occupational Therapy Practitioner:**

Heidi Shaffer, OTR/L, CLT

**Prepared By:**

Bonnie Blair, OTS; Gina Dellino, OTS; Jennifer Thomas, OTS

**Chair:**

Tatiana Kaminsky, PhD, OTR/L

**Course Mentor:**

George Tomlin, PhD, OTR/L, FAOTA

**Date Review Completed:**

May 9, 2017

**Clinical Scenario:**

At the MultiCare lymphedema clinic in Gig Harbor, Washington, occupational therapists work with patients to manage lymphedema: a chronic but manageable condition caused by the buildup of lymph fluid when the lymphatic system is damaged or blocked (Bulley, Gaal, Coutts, Blyth, Jack, Chetty ... Tan, 2013). The majority of patients are referred from oncology seeking treatment for lymphedema consequent to their cancer treatment. Typically, the goal of therapy is to manage lymphedema through manual drainage, care for damaged skin, and compression garments and bandages for an improved HRQoL (Bulley et al., 2013). In 2013, therapists were required to report functional outcomes via G-codes for patients insured by Medicare part B (Doucet, 2013). For patients with lymphedema, HRQoL is an important indicator of function (Morgan, Franks, & Moffatt, 2005). There is a lack of HRQoL measures specific to patients with lymphedema that have psychometric rigor (Mitchell, Gleeson, DiCecco, 2008). Instruments that have completed psychometric testing are important for validating, guiding, and improving the quality of intervention. In addition, these instruments are particularly critical to occupational therapists during a time of increased demands by third party payers to produce function-related outcomes, an integral pillar of occupational therapy practice (Doucet, 2014). Currently, the MultiCare lymphedema clinic is transitioning to using the Lymphedema Life Impact Scale to better understand and report on functional outcomes of treatment.

This critically appraised topic will help to establish the most reliable and valid HRQoL measures to be used for patients with lymphedema by reporting on existing instruments and their psychometric properties. This information will serve the collaborating therapist in selecting the most appropriate outcome measure for clinical use. The therapists at the Multicare lymphedema clinic in Gig Harbor wish to know which HRQoL assessments are most reliable and valid to meet the demands of third party payers and the requirements for G-code reporting set forth by Medicare.

**Review Process**

**Procedures for the selection and appraisal of articles**

**Inclusion Criteria:**

<p>Articles were chosen if:</p> <ul style="list-style-type: none"> <li>• The study examined at least one of the ten HRQoL assessments and derivatives used with the lymphedema population: LLIS, ULL-27, Lymph-ICF, LYMQOL, LyQLI, SF-36, EORTC QLQ-BR23, FACT-B+4, FLIC, or DASH and provided psychometric data.</li> <li>• The study was peer-reviewed.</li> </ul>
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**Exclusion Criteria:**

<p>Articles were excluded if:</p> <ul style="list-style-type: none"> <li>• The study was published prior to 1980.</li> <li>• The study population did not include any patients with cancer and/or lymphedema.</li> <li>• The study is not available in English.</li> </ul>
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**Search Strategy**

Categories	Key Search Terms
Patient/Client Population	Lymphedema, Breast Cancer
Intervention (Assessment)	LLIS (Lymphedema Life Impact Scale), ULL-27, Lymph-ICF, LYMQOL (Lymphedema Quality of Life), LyQLI (Lymphedema Quality of Life Inventory), SF-36 Health Survey, NHP (Nottingham Health Profile), EORTC QLQ-C30 (EORTC QCQ-BR23), FACT-B, FLIC (Functional Living Index-Cancer), or DASH (Disability Arm Shoulder Hand Quality of Life, Functional Outcome Measures
Comparison	
Outcomes	Psychometrics: reliability and validity Development Investigation Evaluation

Databases and Sites Searched
AJOT, BJOT, CJOT
CINAHL
ProQuest
Research Gate (Publications)
Cochrane
MEDLINE
OT Seeker, OT Search

Google Scholar
PubMed
References of References
Citation Tracking

***Quality Control/Review Process:***

Our initial search began by asking the question, “Which functional outcome measures used by lymphedema therapists are best for determining G-codes?” After briefly reviewing the literature and in consult with our chairperson and professors, we decided to eliminate G-codes from our research question and focus on outcome components of lymphedema treatment. Since lymphedema is a chronic condition, one of the main goals of treatment is improved quality of life. As such, our research question was changed to, “Which patient-reported outcome assessments are most valid and reliable in measuring health-related quality of life in patients with lymphedema?”

Based on this question, we generated a list of specific HRQoL assessments that are currently used by lymphedema therapists. We then looked to see if psychometric studies had been completed and if the assessment was feasible within the United States; we eliminated all measures that failed to meet these criteria. Finally, we generated a list of key terms that included common diagnoses seen in this patient population and terms directly from the clinical question to guide our search.

**Results of Search**

**Table 1. Search Strategy of databases.**

Search Terms	Date	Database	Initial Hits	Articles Excluded	Total Selected for Review
Functional outcome measures AND lymphedema	9/22/2016	CINAHL	1	0	1
Functional outcome measures AND lymphedema	10/9/2016	ProQuest	1558	19	1
Functional outcome measures AND lymphedema	10/09/2016	Cochrane	14	14	0 Not relevant or did not meet inclusion criteria.
Functional outcome measures AND lymphedema	10/09/2016	MEDLINE	0	0	0
Functional outcome measures AND lymphedema	10/09/2016	OT Search	0	0	0
Functional outcome measures AND lymphedema	10/09/2016	OT Seeker	0	0	0
Functional outcome measures AND lymphedema	10/09/2016	Google Scholar	10,700	20	0



Functional outcome measures AND lymphedema AND psychometrics	10/09/2016	Google Scholar	1,150	26	1
“Lymphedema functional outcome measure psychometrics”	10/09/2016	Google Scholar	0	0	0
Lymphedema functional outcome measure psychometrics	10/09/2016	Google Scholar	1,200	35	0
Lymphedema AND reliability	10/15/2016	AJOT	6	6	0 Irrelevant
Lymphedema Life Impact Scale	10/18/2016	CINAHL	0	0	0
Lymphedema Quality of Life Inventory (LyQLI)-Development and investigation of validity and reliability	10/18/2016	Primo	2	2	0
Lymphedema Life Impact Scale	10/18/2016	Cochrane	5	5	0
Nottingham Health Profile	10/18/2016	CINAHL	259	39	1 Irrelevant
Nottingham Health Profile AND breast cancer	10/18/2016	CINAHL	2	2	0
EORTC AND reliability	10/18/2016	CINAHL	70	70	0
EORTC AND lymphedema	10/18/2016	CINAHL	5	5	0
Lymph-ICF AND reliability	10/18/2016	Primo	4	2	1 Duplicates
Lymph-ICF	10/18/2016	CINAHL	2	2	0 Duplicates
Lymph-ICF	10/18/2016	PubMed	5	5	0 Irrelevant or duplicates
ULL-27 AND reliability	10/18/2016	PubMed	0	0	0
ULL-27 AND validity	10/18/2016	PubMed	1	1	0 Duplicates
ULL-27	10/18/2016	PubMed	2	2	0
Lymphedema AND reliability	10/18/2016	CINAHL	41	41	0 Duplicates
Lymphedema, quality of life	10/21/2016	Primo	573	52	0

Lymphedema, quality of life inventory	10/21/2016	Primo	237	43	0
Lymphedema life impact scale	10/21/2016	Google Scholar	9, 920	19	1
Lymphedema, quality of life, validity, reliability	10/21/2016	PubMed	15	14	1
LBCQ AND lymphedema	10/21/2016	PubMed	8	8	0
LBCQ AND lymphedema	10/21/2016	ProQuest	17	17	0 (1 used for background)
LBCQ AND reliability	10/21/2016	CINAHL	1	1	0
LBCQ AND validity	10/21/2016	CINAHL	2	0	0 (2 used for background)
LBCQ and lymphedema	10/21/2016	Research Gate (publications)	9	9	0
(FACT-B) AND reliability	10/21/2016	PubMed	20	20	0 (1 used for reference tracking)
LYMQOL	10/21/2016	PubMed	1	1	0
Lymphedema quality of life questionnaire	10/21/2016	CINAHL	2	2	0
Lymphedema quality of life (LYMQOL)	10/21/2016	Google Scholar	71	70	1 Irrelevant or duplicates
Psychometric AND Lymphedema	10/21/2016	CINAHL	6	6	0
Psychometric evaluation of the SF-36 health survey	10/22/2016	PubMed	2	2	2
SF-36 AND lymphedema AND validity	10/22/2016	CINAHL	5	5	0
Nottingham Health Profile, validity, reliability	10/22/2016	Primo	145	50	0
Functional living index cancer AND validity	10/22/2016	PubMed	113	20	0
disability arm shoulder hand AND validity	10/22/2016	PubMed	179	40	0
DASH AND psychometrics	10/22/2016	PubMed	91	20	0

Lymphedema AND reliability	10/22/2016	BJOT	177	40	0 Duplicates or Irrelevant
Lymphedema AND reliability	10/22/2016	CJOT	1	1	0 Irrelevant
Total number of articles used in review from database searches = 8					

**Table 2. Articles from citation tracking.**

Article	Date	Database	Initial Hits	Articles Excluded	Total Selected for Review
Davies, Ryans, Levenhage & Perdomo (2014)	9/22/2016	ProQuest	17	16	1
Total number of articles used in review from citation tracking = 1					

**Table 3. Articles from reference tracking.**

From Article	Date	Articles Referenced	Articles Excluded	Total Selected for Review
Davies, Ryans, Levenhage & Perdomo (2014)	10/18/2016	31	27	4
Wilson, R. W., Hutson, L. M. & VanStry, D. (2005)	10/18/2016	37	36	1
Maratia, S., Cedillo, S. & Rejas, J. (2016)	10/21/2016	62	57	5
Total number of articles used in review from reference tracking = 10				

CAT Table 4: Descriptive Studies

Author, Year, Journal Abbreviation	Study Objectives	Study Design/ Level of Evidence	Assessments or screens being compared	Population/ Setting	Psychometrics	Summary of results	Limitations
Brady, Cella, Mo, Bonomi, Tulskey, Lloyd, Deasy, Cobleigh, Shiomoto (1997), JCO	Validation of the FACT-B	AOTA level: IV  Pyramid level: D2	FACT-B - FACT-G  BC-Subscale  FLIC  PSR	First sample: Patients w/ advanced BC, completed FACT-B version 1, treated at Rush-Presbyterian-St. Luke's Medical Center. Patients tested twice over 2 months.  $N = 47$  Second sample: Adults w/ BC, w/o brain metastasis, not using psychotropic drugs, and completed version 3 of the FACT-B; recruited from 3 medical centers  $N = 295$	<b>Cronbach's <math>\alpha</math>:</b> 0.63-0.90  <b>Test-retest reliability:</b> Correlation coefficients: 0.88 for BC-Subscale, 0.89 for TOI-PFB, & 0.85 for FACT-B total score, indicating high degree of stability (3 to 7 days)  <b>Validity:</b> The first sample demonstrated sensitivity to change on the total score, the PWB subscale, FWB subscale, and the BC-Subscale with ( $F(df=12,78) = 2.59; p = 0.006$ )  <b>Construct validity:</b> FLIC ( $r=0.87; p < 0.001$ ), FACT-G total score ( $r=0.86; p < 0.001$ ), TOI-PFB ( $r=0.86; p < 0.001$ ), and BC-Subscale ( $r=0.53; p < 0.001$ ) for first sample.  <b>Known-groups validity:</b>	FACT-B is appropriate for use in oncology clinical trials and clinical practice. Demonstrates ease of use, brevity, reliability, validity, and sensitivity to change.	Must be administered in its entirety; no limitations listed or found in the study design.

					$F(18, 784) = 10.27; p < 0.001$		
Coster, Poole, & Fallowfield (2001), BCRT	Document the validation of the FACT-B w/ the addition of the 4-item arm subscale and the sensitivity to effects of arm morbidity.	Prospective longitudinal correlation study  AOTA level: IV Pyramid level: D2	FACT-B+4  FACT-B	<p><u>Group 1</u> <i>Population/Setting:</i> Participants in phase 1 of the ALMANAC study, under the care of breast cancer surgeons in the UK.  <i>N:</i> 279</p> <p><u>Group 2</u> <i>Population/Setting:</i> Women with known chronic arm morbidity attending a lymphoedema clinic.  <i>N:</i> 29</p>	<p><b><i>Cronbach's <math>\alpha</math>:</i></b> 0.62 for BC subscale, 0.88 for total FACT-B+4 score, 0.83 for arm subscale.</p> <p><b><i>Test-Retest reliability:</i></b> Total arm subscale (<math>r=0.93</math>), FACT-B+4 (<math>r=0.97</math>) over 5-day period for group 2. Group 2 scored lower on all QoL subscales, except EWB, than a subset of group 1.</p> <p><b><i>Non-parametric chi-squared:</i></b> On all arm items was significant, <math>p=0.001</math>, 89.36-13.47, <math>df=4</math>) between the 2 groups.</p> <p><b><i>Sensitivity to change over time:</i></b> Was significantly lower 4 weeks post baseline (prior to surgery) measures for mean scores (<math>p=0.001</math>), arm subscales increased significantly from baseline measures (<math>p=0.01</math>).</p>	FACT-B+4 appears to be psychometrically sound. It is suitable to be used in longitudinal surgical trials. Reliability is comparable to previous validation studies. Good test-retest reliability. There is reliable discrimination between patients w/ and w/o severe arm morbidity. Arm subscale and FACT-B+4 were sensitive to changes in arm condition over time. Patients found the scale easy to complete.	Study failed to identify limitations of the design, including patients recruited instead of randomly selected. Study only looked at change over 12 weeks. Not necessarily generalizable to men.

Davies, Brockopp, & Moe (2015), RO	Determine the psychometrics, including test-retest and internal consistency for using the DASH with BC survivors with 2° lymphedema.	Retrospective Correlational Study  AOTA level: IV Pyramid level: D2	DASH	<p><i>Population:</i> Women diagnosed with BC, with secondary lymphedema. Mean age of 60yo</p> <p><i>Setting:</i> Outpatient rehabilitation department of a Magnet re-designated community hospital.</p> <p><i>N:</i> 163</p>	<p><b><i>Cronbach's <math>\alpha</math>:</i></b> Initial evaluation=0.97, 30-day re-evaluation=0.92, discharge=0.92</p> <p><b><i>Test-retest:</i></b> ICC=0.97</p>	The DASH is found to have strong test-retest reliability and internal consistency for measuring upper extremity function among BC survivors with lymphedema.	Clients' recall of previous answers on the assessment may have affected test-retest outcomes. First study to look at this demographic with the DASH. Not necessarily generalizable to men with lymphedema.
Devoogdt, Groef, Hendrickx, Damstra, Christiaan, Geraerts... Kampen, (2014), PT	Develop the Lymph-ICF-LL (phase 1) and to determine the reliability and validity of the Lymph-ICF-LL (phase 2)	Correlational study  AOTA level: IV Pyramid level: D2	Lymph-ICF-LL - Compared to: SF-36 FLQA-I	<p><u>Phase 1</u> <i>Population:</i> Men (20%) &amp; women (80%) averaging 58.7 yo. who spoke Dutch Diagnosed w/ 2° LE lymphedema</p> <p><i>Setting:</i> Leuven Lymphoedema Center (Belgium)</p> <p><i>N:</i> 20</p> <p><u>Phase 2</u></p>	<p><b><i>Reliability</i></b> Test-retest: 0.69-0.94 (correlation coefficient) Internal Consistency: 0.82-0.97 (Cronbach <math>\alpha</math>) Measurement Variability: acceptable; SEM = 5.9 - 12.6</p> <p><b><i>Validity</i></b> Content: good; questions understandable (93% of participants), questionnaire</p>	The Lymph-ICF-LL has strong face, construct, and content validity. It has strong reliability with high intra-class correlation coefficients. Developers provide suggestions for improving 4 questions that rated moderate for test-retest reliability via administration.	Only tested Dutch version of measure. Phase 1 participant diagnoses differed from those of phase 2. Responsiveness of the Lymph-ICF-LL and known-groups validity was not tested for.

				<p><i>Population:</i> Men (20%) &amp; women (80%) averaging 51 yo. and spoke Dutch Diagnosed w/ 1° or 2° LE lymphedema</p> <p><i>Setting:</i> Lymphedema clinic at Nij Smellinghe Hospital (Netherlands) (n= 11), Leuven Lymphedema Center (Belgium) (n= 19)</p> <p>N= 30</p>	<p>comprehensive (90% of participants) Construct: good; all hypotheses for convergent and divergent validity accepted (correlation coefficients for convergent validity ranged from -0.46 to -0.86 and divergent validity ranged from 0.04 to -0.32).</p>	<p>(24/28 questions very strong – strong).</p>	
Devoogdt, Kampen, Geraerts, Coremans, & Christiaens (2011), PT	Investigate the reliability and validity of data collected by the final version of the Lymph-ICF	Correlation al study  AOTA level: IV, Pyramid level : D2	Lymph-ICF - Compared to SF-36	<p><i>Population:</i> Women w/ BC having undergone unilateral axillary dissection &lt;12 months prior to study. Dutch speaking.</p> <p><i>Setting:</i> Department of Physiotherapy of the University Hospital, Leuven</p> <p>N= 90 (n= 60 w/ lymphedema, n=30 w/o lymphedema)</p>	<p><b>Reliability</b> <i>Test-retest:</i> r =0.65 -0.93 <i>Internal Consistency:</i> &gt; 0.77 (Cronbach's <math>\alpha</math>) <i>Measurement Variability:</i> acceptable; SEM = 4.8-12.5</p> <p><b>Validity</b> <i>Content:</i> good; questions understandable, clear scoring system for 88% of participants, lymphedema complaints</p>	The final version of the Lymph-ICF is a reliable and valid Dutch questionnaire to assess functional problems (as defined by the WHO-ICF) for patients with lymphedema 2° to axillary dissection.	Study did not investigate responsiveness. Focus on Dutch version, limits generalizability to the USA. Lack of detail for participant characteristics in phase 1 and use of researcher developed questionnaire to determine content validity introduces bias and perhaps confounding

					mentioned by 85% of participants <i>Construct:</i> good; convergent validity confirmed by 5 domains on Lymph-ICF correlating strongest w/ 5 expected domains of SF-36; divergent confirmed 3/5 hypotheses accepted.		variables (within participant characteristics). Participants may have had trouble distinguishing between complications due to lymphedema versus BC treatment. Women only.
Keeley, Crooks, Locke, Veigas, Riches Hilliam, (2010), JL	Describe the validation of a condition-specific QoL measure for lymphedema of the limbs.	Retrospective correlational study  AOTA level: IV Pyramid level: D2	LYMQOL - Compared to: EORTC QLQ-C30	New patients presenting to the clinic. Mean age: 58 years (SD 16.4 years). 78% were women, bilateral leg swelling was the most frequently reported (43.8%), 26.8% reported unilateral arm swelling, 27.7% unilateral leg swelling, 1.5% reporting combination of arm and leg swelling  <i>N</i> = 209	<b>Face validity:</b> Was confirmed with questionnaire, content validity established via phenomenological interview of 22 patients  <b>Correlation coefficient:</b> for arm ranged from 0.689-0.937 and for leg from 0.644-0.788 respectively w/ comparable domains in the EOC QLQ-C30.	LYMQOL is a validated QoL assessment for use w/ people w/ limb lymphoedema	Limitations not listed, full psychometric data findings from previous 2004 study not listed
Klernäs, Johnsson, Horstmann, Kristjanson, & Johansson (2015), QLR	Reduce the SLQOLI from 188 items to 45 items to create the LyQLI. Determine psychometrics of the LyQLI,	Correlational Study  AOTA level: IV Pyramid level: D2	LyQLI - Adapted from SLQOLI - Compared against SF-36	<b>Population/Setting:</b> Outpatients from the registers of the lymphedema units at Skane University Hospital and Red Cross Hospital, Solna, Sweden. Adults diagnosed with lymphedema >6months.	<b>Inter-rater reliability:</b> Using ICC for physical, psychosocial and practical domains on the shorter instrument were 0.88 ( $p<0.01$ ), 0.87 ( $p<0.01$ ), and 0.87 ( $p<0.01$ ).	The LyQLI shows promise for clinical settings and future studies for those with lymphedema. Shown to have very good internal consistency reliability. Concurrent validity was shown through	No patient expert group evaluated in final questionnaire. Percentage of missing items for the patients ranged from 0 to 14.6%, mean scores were used instead. Patients instructed not to receive additional



	including stability over time and concurrent validity.			<i>N</i> : 200 (100/site) contacted, 130 participated.	<p><b>Cronbach's <math>\alpha</math>:</b> 0.88, 0.92, 0.88 – Physical, psychosocial, &amp; practical domains, respectively.</p> <p><b>Concurrent Validity:</b> Scores of the three domains of the shortened LyQLI with scores of the PCS and MCS in the SF-36 were all <math>r_s &gt; 0.60</math>.</p>	correlation with the SF-36 for all domains.	treatment, not verifiable. Patients may have improved due to time of year or expectations effect. Did not assess the sensitivity of the LyQLI.
Launois, Megnigbeto, Pocquet, & Alliot (2002), L	Administer validity testing as a final step in development of ULL-27	Correlation al study  AOTA Level: IV Pyramid Level: D2	ULL-27 - Compared against SF-36, GSI, ACS, GCI	<p><b>Population:</b> Women aged &gt; 18 yo. (average age = 61 yo.) of all educational levels previously treated with surgery, radiotherapy, chemotherapy, or hormone therapy.</p> <p><b>Diagnoses:</b> Upper limb lymphedema stages 1-4, 2° to BC. 47% had a history of lymphangitis.</p> <p>Setting: multiple centers</p> <p><i>N</i> = 301</p>	<p><b>Internal Consistency:</b> Physical = 0.93 Psychological= 0.86 Social = 0.82 (Cronbach's <math>\alpha</math>)</p> <p><b>Effect Size in patients who improved clinically:</b> Physical = 0.58 Psychological= 0.62 Social= 0.38</p>	ULL-27 is shown to be valid and reliable. Scores for physical and social dimensions significantly correlated to illness severity. Social dimension is sensitive to clinical changes in lymphedema while physical and psychological dimensions do not change in clinically stable patients.	Measurement tool was developed in France for French speaking patients limiting generalizability for practitioners in other countries. Methodology & results for comparison to SF-36 are brief, limiting ability to reproduce methods or compare results. Setting is unclear. Poor quality of research translation from French to English language affecting interpretation of results.
Morrow, Lindke, & Black (1992), QLR	Examine psychometrics of the FLIC, including	Correlation al Study  AOTA level: IV	FLIC	<p><b>Population:</b> Patients being treated w/ chemotherapy. Age: 18-76.</p>	<p><b>Construct validity:</b> 18/22 questions had factor loading &gt; 0.40 on only 1 of 5 factors. 4 questions addressing</p>	FLIC appears to be a valid and internally consistent instrument. There is strong evidence for	The study failed to identify limitations in the design, such as all clients recruited from one cancer center.

	construct validity	Pyramid level: D2		<p><i>Setting:</i> University of Rochester Cancer Center.</p> <p><i>N:</i> 489, originally recruited 530</p>	<p>cancer had loading &gt; 0.40 on 2+ factors.</p> <p><b>Criterion-related validity:</b> Low side-effects and anxiety result in higher QoL scores. Females had higher physical &amp; social functioning scores.</p> <p><b>Internal consistency:</b> Cronbach's <math>\alpha = 0.90</math> (original sample), 0.94 (validation sample)</p>	construct validity, and factors were sensitive to meaningful differences. The 4 cancer related questions should be omitted to create a better fit of the data to the factor model.	The study looked broadly at cancer, limiting generalizability to lymphedema.
Patoo, Allahyari, Moradi, & Payandeh (2015), APJCP	Assess the validity of the FACT-B when used for Iranian women w/ BC.	Correlational study  AOTA level: IV Pyramid level: D2	FACT-B (Persian Version) - compared against HADS anxiety and depression and the EORTC QLQ-C30	<p><i>Population/Setting:</i> Women recruited from oncology clinics and hospitals in Iran. Pathologic diagnosis of cancer.</p> <p><i>N:</i> 300</p>	<p><b>Internal consistency:</b> Cronbach's <math>\alpha</math>: 0.93-0.63 for subscales, 0.92 total scale.</p> <p><b>Convergent validity:</b> All interscale correlations <math>p &lt; 0.01</math>, except SFWB and PWB</p> <p><b>Discriminant validity:</b> correlation between all Persian FACT-B subscales and HADS statistically significant.</p> <p><b>Concurrent and construct validity:</b> Except SFWB, all subscales of FACT-B significantly correlated w/ EORTC-QLQ-C30 Fit indices showed modest fit of the model.</p>	The Persian version of FACT-B is reliable and valid in assessing HRQoL of Iranian BC patients.	Validation of a translated version of FACT-B, not original. Cultural differences of Iranian women, including taboo nature of speaking about sexuality limits generalizability to USA. Study failed to identify specific limitations. Limited information regarding patient recruitment process.

<p>Sprangers, Groenvold, Arraas, Frnklin, Velde, Mulle... Aaronson, (1996), JCO</p>	<p>Develop a BC specific QoL questionnaire used in tandem w/ the EORTC QLQ-C30</p>	<p>AOTA level: IV  Pyramid level: D2</p>	<p>QLQ-BR23</p>	<p>Dutch Sample: Participants had BC and were receiving either radiotherapy or chemotherapy. <i>Setting:</i> Antoni van Leeuwenhoek Hospital, Amsterdam  N = 170  Spanish Sample: Participants had BC and were receiving either radiotherapy or chemotherapy. <i>Setting:</i> Hospital de Navarra, Pamplona  N = 168  American Sample: Participants had BC and were either about to start treatment or were in follow up care. <i>Setting:</i> M.D. Anderson Cancer Center, Houston, TX  N = 158</p>	<p><b>Reliability:</b> Cronbach’s <math>\alpha</math>: Dutch = 0.57 - 0.89 Spanish = 0.46 – 0.94 American = 0.70 – 0.91  <b>Validity:</b> Spanish effect sizes: medium (0.60-0.68) Dutch effect sizes: medium-large (0.43-1.1) American sample did not achieve statistical significance.</p>	<p>Validity demonstrated by test’s ability to discriminate amongst subgroups with different clinical statuses and across cultures. Reliability lowest in Spanish sample and highest in American sample.</p>	<p>Scores measuring clinical state of health were not completely comparable as Spanish patient information was provided by physician and Dutch sample was interviewer based. Questions about sexuality were considered too intrusive for some female participants and were unanswered.</p>
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<p>Van de Pas, Biemans, Boonen, Viehoff &amp; Neumann (2015), P</p>	<p>Test the psychometric properties and validate use of a Dutch translation of the LYMQOL Questionnaire</p>	<p>Correlational study  AOTA Level: IV Pyramid level: D2</p>	<p>LYMQOL SF-36</p>	<p>60 patients diagnosed at an academic institution completed questionnaire. Response rate was 88.2%, 70% were women. Mean age: 60 SD: 15.6 years Range: 19-92. Most had bilateral leg 2° lymphedema. Classified according to duration of lymph: 0-5 yrs: 19.4% 5-10 yrs: 22.4% 10-20 yrs: 28.4% 20+ ys: 29.9%</p> <p>Most patients wore compression stockings</p>	<p><b>Internal Consistency:</b> Cronbach’s <math>\alpha</math>: 0.89</p> <p><b>Test-retest reliability:</b> Excellent, w/ <math>\rho &gt; 0.8</math> for all domains, and overall QoL was good, w/ <math>\rho &gt; 0.7</math></p> <p><b>Validity:</b> The LYMQOL correlated well w/ the PCS and moderately well with the MCS of the SF-36</p>	<p>The Dutch LYMQOL is a feasible, reliable, and valid tool in the assessment of HRQoL in patients w/ LE lymphedema.</p>	<p>Generalizability limited due to non-randomized sample and Dutch population</p>
<p>Viehoff, Genderen, &amp; Wittink,(2008), L</p>	<p>Validate a version of the ULL-27 translated to Dutch</p>	<p>Correlational study  AOTA: IV Pyramid: D2</p>	<p>ULL-27 (Dutch version) - Compared against the SF-36</p>	<p><b>Population:</b> Women (mean age= 59) fluent in Dutch. 94% had axillary surgery. Diagnosed w/ unilateral edema of the UE</p> <p><b>Setting:</b> 29 lymphedema physiotherapy specialist practice settings</p> <p>N= 84</p> <p><b>Comparison Population:</b> An age-matched group of women without symptoms</p> <p>N=61</p>	<p><b>Internal consistency:</b> good; all <math>&gt; 0.70</math> (Cronbach’s <math>\alpha</math>)</p> <p>Item domain internal consistency sufficient except for 2 questions (#20 &amp; #22)</p> <p><b>Concurrent Validity:</b> domains of Dutch ULL-27 significantly correlated to 5 of 8 corresponding SF-36 domains</p>	<p>No distinction between 4 grades of severity in Dutch version (inconsistent with original version of ULL-27), similar internal consistency (good) to original version, physical domain of ULL-27 poorly correlated to SF-36</p>	<p>Participant characteristics (amongst types of severity) do not match that of the original validation study making direct comparison impossible; comparison group consisted of physiotherapist’s friends and family introducing bias</p>

<p>Weiss &amp; Daniel (2015), L</p>	<p>Assess the reliability and validity of the LLIS as a condition-specific instrument for persons with lymphedema.</p>	<p>Correlational cohort study  AOTA level: IV Pyramid level: D2</p>	<p>LLIS - Compared to: LYMQOL EORTC QLQC30 DASH LEFS</p>	<p><i>Population/Setting:</i> Adult patients w/ lymphedema (except controls which comprised of patients at risk for lymphedema) recruited from lymphedema therapy clinics across the US.  N=102</p>	<p><i>Internal consistency:</i> Cronbach's <math>\alpha</math>: .841-.926  <i>Test-retest reliability:</i> .97-.99  <i>Construct validity:</i> <math>r = .706-.830</math></p>	<p>The LLIS was demonstrated to be a valid and reliable QoL tool for assessing severity of impairment among patients w/ lymphedema.</p>	<p>Most participants were white females limiting generalizability across gender and race.</p>
<p>Wilson, Hutson, &amp; VanStry (2005), PT</p>	<p>Assess convergent validity and discriminative validity of SF 36 and FLIC</p>	<p>Correlational study  AOTA level: IV Pyramid level: D2</p>	<p>RAND 36-Item Health Survey (SF-36)  FLIC</p>	<p><i>Population:</i> Women w/ BC, who received surgical intervention &gt; 3mo prior. Age: 18-65yo.  <i>Setting:</i> National Cancer Institute-designated Comprehensive Cancer Center  N: 110 (n=32 w/ 2° lymphedema)</p>	<p><i>Bivariate correlations:</i> SF-36 mental &amp; physical component tau-b=0.247. SF-36 mental component &amp; FLIC total tau-b=0.490. SF-36 physical component &amp; FLIC total tau-b=0.556.  <i>Convergent/Divergent Validity:</i> Comparisons of pairs of subscales of QoL domains showed convergent correlations in the physical domain (<math>\chi^2=20.48, p&lt;0.001</math>), mental well-being domain (<math>\chi^2=7.68, p&lt;0.01</math>), &amp; social functioning (<math>\chi^2=4.45, p&lt;0.05</math>). However, convergence within the general health dimension was not significant</p>	<p>Neither questionnaire can replace the other for women with BC. The modest correlations between the SF-36 and FLIC suggest they measure somewhat different aspects of HRQoL. The FLIC was more sensitive to differences in EWB. Both FLIC and SF-36 were able to distinguish deficits in physical functioning in the group with lymphedema.</p>	<p>Clinic data influencing HRQoL was not collected, limiting generalizability. Only compared two instruments, limiting convergent validity measures. Population limited to women w/ BC more than 3 months post-surgical intervention.</p>

					<p>(<math>\chi^2=3.27, p &lt; 0.1</math>),          indicating these similarly          named subscales          measure different QoL          dimensions in this          sample.</p>		
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**CAT Table 5: Systematic Reviews**

Author(s), Year	Study Objectives	Study Design/ Level of Evidence	Number of Papers Included, Inclusion and Exclusion Criteria	Outcome Measures	Summary of Results	Limitations
Davies, Ryans, Levenhage, & Perdomo (2014), RO	Identify outcome measures targeting QoL and function specific to UE secondary lymphedema, review psychometrics, and make clinical recommendations	Systematic Review  AOTA Level: I  Pyramid Level: D1	<i>Papers Included: 42</i>  <i>Inclusion Criteria:</i> UE secondary lymphedema, female, adult, breast neoplasm,  <i>Exclusion Criteria:</i> primary lymphedema, LE, venous, male gender, lack of psychometric properties	FACT-B +4, DASH, ULL-27, Lymph-ICF, LYMQOL	<i>FACT-B+4</i> Highly recommended due to test-retest reliability, overall internal consistency; unknown clinical utility <i>DASH</i> Highly recommended for test-retest reliability, internal consistency, validity, and sensitivity to change (MCID=10.2); good clinical utility <i>ULL-27</i> Unable to recommend at this time <i>Lymph-ICF</i> Unable to recommend at this time (no sensitivity reported, lack of clinical use in U.S.) <i>LYMQOL</i> Unable to recommend at this time (in development phase)	Limited to UE assessments and BCRL, Recommendations based on Breast Cancer EDGE Task Force ratings and definitions for clinical utility could contain bias.

<p>Oliveira, Costa, Gafundes, &amp; Cabral (2015), QLR</p>	<p>Identify BC specific questionnaires that have been cross-culturally adapted and critically analyzed for quality of translation, adaptation, and evaluation of measurement properties</p>	<p>Systematic Review  AOTA level: I  Pyramid level: D1</p>	<p><i>Papers Included:</i> 24 <i>Inclusion Criteria:</i> Studies from any year or language assessing BC-specific QoL questionnaires translated into a language besides source language. Studies exclusive to women with BC.</p>	<p>EORTC QLQ-BR23 FACT-B FACT-B+4 IBCSG LSQ-32 QLICP-BR</p>	<p>Shortcomings in global BC QoL instruments. Over half of articles had no information for translation and cross-cultural adaptation. EORTC QLQ-BR23 in Spanish and Korean highest level of translation and cultural adaptation. Internal consistency doubtful in 15 articles. Construct validity adequate in 3 studies (FACT-B, EORTC, &amp; QLQ-BR23). 4 of 8 articles positively reported reliability.</p>	<p>Studies evaluated by one set of guidelines. Cross-cultural validation and measurement properties of a QoL questionnaire are complex and subject to misinterpretation.</p>
<p>Pusic, Cemal, Albornoz, Cano, Sulimanoff, Hernandez, Massey, Cordeiro, Morrow, &amp; Mehrara (2013), JCS</p>	<p>Identify studies describing HRQOL outcomes in BCRL patients, assess quality of studies, &amp; assess PRO instruments</p>	<p>Systematic Review  AOTA Level 1  Pyramid level D1</p>	<p>39 studies; inclusions: BCRL, described HRQOL outcomes among BCRL, English only, formally developed, valid PROs. Exclusion: No conference abstracts, no BC in men</p>	<p>4 generic HRQOLs, 9 oncology-specific, 2 BCRL-specific</p>	<p>ULL-27 recommended b/c of strong psychometric properties, generic PRO should be used alongside condition-specific PRO</p>	<p>BCRL only, English only, women only. No non-validated, modified standardized instrument. The article did not contain list of databases used for identifying articles.</p>



<p>Treanor &amp; Donnelly (2015), QLR</p>	<p>Review studies investigating the validity, reliability, and sensitivity of the SF-36 and its derivatives among BC survivors.</p>	<p>Systematic Review AOTA level: I Pyramid level: D1</p>	<p><i>Papers included:</i> 7 PubMed, MEDLINE, EMBASE, CINAHL, PsycINFO and the Social Sciences Citation Index search engines were used with keyword search terms. Reference lists of retrieved articles were reviewed for relevant contributing articles.  <i>Inclusion criteria:</i> Articles including survivors of BC; using SF measures to assess psychometrics of other measures, peer-review articles  <i>Exclusion Criteria:</i> No exclusions were made due to the small number of papers identified</p>	<p>SF-36 partial SF-36 SF-12 FACT-B FACT-G</p>	<p><b>Internal Consistency:</b> SF-36 and SF-12 subscales ranged from acceptable to good across different language and ethnic groups.  <b>Concurrent validity:</b> Good inter-correlation between Dutch SF-36 and lymphedema-specific measures (ULL27 and Lymp-ICF), but less strong correlation with physical subscales. SF-36 discriminated between BC survivors w/ and w/o lymphedema on physical subscales.  <b>Conclusions:</b> SF measures were found to have good psychometric properties and would provide a useful aide for health care providers to assess health-related outcomes of breast cancer survivors in their care. Further research needed to identify psychometric performance of SF-36 on cancer-related effects.</p>	<p>Articles which scored ‘poor’ on one item on the COSMIN checklist may have received an overall ‘poor’ rating. Inclusion of additional studies which did not primarily assess psychometric properties of SF may be questionable. Many psychometric properties of the SF-36 were not assessed in the breast cancer population.</p>
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*Summary of Study Designs of Articles Selected for the CAT Table*

<b>Pyramid Side</b>	<b>Study Design/Methodology of Selected Articles</b>	<b>Number of Articles Selected</b>
Experimental	___ Meta-Analyses of Experimental Trials ___ Individual Randomized Controlled Trials ___ Controlled Clinical Trials ___ Single Subject Studies	
Outcome	___ Meta-Analyses of Related Outcome Studies ___ Individual Quasi-Experimental Studies ___ Case-Control Studies ___ One Group Pre-Post Studies	
Qualitative	___ Meta-Syntheses of Related Qualitative Studies ___ Small Group Qualitative Studies ___ brief vs prolonged engagement with participants ___ triangulation of data (multiple sources) ___ interpretation (peer & member-checking) ___ a posteriori (exploratory) vs apriori (confirmatory) interpretive scheme ___ Qualitative Study on a Single Person	
Descriptive	_4_ Systematic Reviews of Related Descriptive Studies 15_ Association, Correlational Studies ___ Multiple Case Studies (Series), Normative Studies ___ Individual Case Studies	19
Comments: The majority of studies were correlational studies evaluating psychometric properties. Four studies were literature or systematic reviews comparing psychometrics across assessments. AOTA Levels I- 4 II- III- IV- 15 V-		<i>TOTAL =19</i>

<b>Abbreviation</b>	<b>Full Phrase</b>
1°	Primary
2°	Secondary
ACS	Patient's arm comfort scale
ALMANAC	Axillary lymphatic mapping against nodal axillary clearance
BC	Breast cancer
BCRL	Breast cancer related lymphedema

COSMIN	Consensus-based Standards for the Selection of Health Measurement Instruments
DASH	Disability of Arm, Shoulder, and Hand
EDGE	Evaluation database to guide effectiveness
EMR	Electronic medical record
EORTC QCQ-BR23	European Organization for Research and Treatment of Cancer-specific quality of life questionnaire- breast cancer 23
EORTC QCQ-C30	European Organization for Research and Treatment of Cancer-specific quality of life questionnaire-cancer 30
EWB	Emotional well-being
FACT-B, FACT-B+4	The Functional Assessment of Cancer Therapy - Breast
FACT-G	Functional Assessment of Cancer Treatment - General
FLIC	Functional Living Index-Cancer
FWB	Functional well-being
GCI	Global clinical impression
GSI	Global symptom index
HADS	Hospital Anxiety and Depression Scale
HOS	Health outcome survey
HRQoL	Health-related quality of life
IBCSG	International Breast Cancer Study Group
ICC	Intra-class correlation
LE	Lower extremity
LEFS	Lower extremity functional scale
LLIS	Lymphedema Life Impact Scale
LSQ-32	Life Satisfaction Questionnaire – 32
Lymph-ICF	Lymphoedema Functioning, Disability, and Health Questionnaire
Lymph-ICF-LL	Lymphoedema Functioning, Disability, and Health Questionnaire for Lower Limb Lymphedema
LYMQOL	Lymphedema Quality of Life Measure for Limb
LyQLI	Lymphedema Quality of Life Inventory

MCID	Minimal clinically important difference
MCS	Mental component summary measure
NHP	Nottingham Health Profile
PCS	Physical component summary measure
PSR	Performance status rating
PRO	Patient reported outcomes
PWB	Physical well-being
QLICP-BR	Quality of Life Instrument for Cancer Patients-breast cancer
QoL	Quality of life
SD	Standard deviation
SEM	standard error of measure
SF	Short Form
SF-12	Short Form-12
SF-36	Short Form-36
SFWB	Social and family well-being
SLQOLI	Swedish Lymphedema Quality of Life Inventory
TOI-PFB	Trial Outcome Index – Physical/Functional/Breast
UE	Upper extremity
UK	United Kingdom
ULL-27	Upper limb lymphedema measure
w/	With
w/o	Without
yo	years-old

**Summary of Key Findings:**

## Summary of Experimental Studies

N/A

## Summary of Outcome Studies

N/A

## Summary of Qualitative Studies

N/A

## Summary of Descriptive Studies

The DASH questionnaire consists of 30 items that evaluate symptoms and functional tasks associated with limitations in the arm, shoulder, and hand. It demonstrated strong reliability, validity, and sensitivity to change in women with BC. The tool has been widely used in BC research and clinics on patients with and without lymphedema since its inception in the mid-1990s (Coster, Poole, & Fallowfield, 2001; Davies et al., 2015).

The Functional Living Index-Cancer (FLIC) is a broad-based assessment tool developed in the early 1990s to measure HRQoL for patients with cancer. The physical function domain of the assessment discriminates patients diagnosed with lymphedema. The instrument is more sensitive to emotional well-being than the SF-36 (Morrow, Lindke & Blacke, 1992; Wilson, Hutson & VanStry, 2005).

The FACT-B+4 consists of 36 items with four questions addressing swelling and tenderness in the arm. It was developed to supplement the FACT-B, the original multi-dimensional breast cancer QoL tool. It has been tested on women with lymphedema secondary to BC. This tool has strong reliability, internal consistency, and sensitivity to change over time with women with BC (Brady et al., 1997; Coster, Poole, & Fallowfield, 2001; Davies et al., 2015).

The LLIS is a new lymphedema-specific assessment tool designed for use in the U.S. for calculating G-codes. The LLIS was compared to the LYMQOL, EORTC QLQ30, DASH, and LEFS and demonstrated good validity and reliability for assessing lymphedema severity among adult patients (Weiss & Daniel, 2015). The LLIS correlated more strongly with the LYMQOL than the others, except for the functional domain of the DASH. A limitation was a sample comprised largely of white females (Weiss & Daniel, 2015).

The LyQLI is a new lymphedema-specific Swedish assessment tool adapted from the SLQOLI as of 2015. It was compared to the SF-36 and shown to have good reliability and validity. Results indicate that the assessment tool holds promise. Sensitivity not tested (Klernas, Horstmann, & Kristjansson, 2015).

The Lymph-ICF was created in 2011 for patients with upper limb lymphedema (Devoogdt et al., 2011). Initial psychometric testing revealed strong test-retest reliability, internal consistency, content validity, and construct validity when compared against the SF-36 (Davies et al., 2015; Devoogdt et al., 2011). Women and Dutch populations were predominantly studied when establishing psychometric properties of this measurement device. There is no evidence of clinical use in the U.S. (Davies, 2015).

The Lymph-ICF-LL was created in 2014 for patients with lower limb lymphedema (Devoogdt et al., 2014). Initial psychometric testing demonstrated that it was a reliable and valid measure, but similar to the Lymph-ICF, this instrument has only been tested on Dutch populations with lymphedema secondary to axillary dissection (Devoogdt et al., 2014).

The ULL-27 was developed in France in 2002 for measurement of upper limb lymphedema. It tests physical, social, and psychological domains. Initial testing of the psychometrics report that the test is reliable, consistent, and responsive to change (Launois et al., 2002). This measurement tool has been translated into English and Dutch, but only the Dutch version has undergone psychometric testing after adaptation and translation (Davies et al., 2015). The Dutch version translation demonstrated internal consistency on all items with exception of two questions which are addressed by Viehoff, Van Genderen, and Wittink (2008). The physical domain of this version poorly correlated to the SF-36 (Viehoff et al., 2008).

The LYMQOL's psychometrics were listed by a secondary study, but the primary study was not obtained through available resources. However, a Dutch version that tested psychometric properties demonstrated good validity and reliability for assessing HRQoL in patients with lower limb lymphedema (Van de Pas, Biemans, Boonen, Viehoff, & Newmann, 2015). The LYMQOL was developed with a structure similar to EORTC

QLQ-C30. Results state assessment is a validated QoL for use with persons with lymphoedema, and systematic review cites similar findings (Davies, Ryans, Levenhagan, & Perdomo, 2014).

The EORTC developed the QLQ-C30 and the QLQ-BR23 to measure quality of life among patients with BC. The test has been translated to various languages and in one study demonstrated good reliability, clinical, and cross-cultural validity for the Dutch, Spanish, and American versions (Sprangers et al., 1996).

### **Implications for Consumers:**

While secondary lymphedema is often associated with patients undergoing cancer treatment, it is also experienced as a result of trauma or parasitic infection or where there is damage to the lymphatic system (Morgan, Franks, & Moffatt, 2005). Swelling, skin changes, fibrosis, sensory impairments, pain, discomfort, heaviness in the affected limb, and secondary infections are common symptoms associated with lymphedema (Morgan et al., 2005). Understanding the HRQoL for patients with lymphedema is consistent with client-centered treatment. Since improvement of HRQoL is the primary aim of lymphedema treatment, it is imperative that valid and reliable measures are used to best capture this condition-specific experience. This critical appraisal demonstrates that outcome measurements for lymphedema treatment are varied in their approach (generic versus condition-specific) and include different areas of HRQoL. Consumers should take note of the types of outcome measures used by lymphedema therapists during treatment and evaluate the accuracy of results against subjective experience. If a patient with lymphedema feels that outcomes are not consistent with instrument results, or that a selected measure is not appropriate for his or her case, this critically-appraised topic can serve as a resource for advocacy. A patient with lymphedema should advocate for the most valid and reliable measurement of outcomes for purposes of adjusting treatment for optimal gains.

### **Implications for Practitioners:**

This critically appraised topic is especially important to occupational therapists specializing in lymphedema. The 2013 mandate by Medicare to report G-codes, a functional status for patients across points of treatment, highlights a trend towards defining successful treatment as it relates to function (Doucet, 2014). This focus on functional activities has been a tenet of occupational therapy since its inception. Doucet (2014) describes this as a “critical” time for occupational therapists to assert the unique scope and domain of function in their practice. In order to capitalize on this opportunity, the use of valid and reliable measures to document function is essential. Psychometrically-sound measurement instruments arm practitioners with objective data to quantify the effectiveness of interventions on everyday functioning. This information works to demonstrate the effects of treatment to third-party payers for purposes of reimbursement. Practitioners specializing in lymphedema therapy define function as it relates to HRQoL. Hence, it is fundamental for this sub-field of occupational therapy to incorporate outcome measures that reliably and accurately target condition-specific HRQoL. Since research on condition-specific measurements is still in its infancy, practitioners should evaluate the characteristics of each device against a client's specific presentation (i.e., comorbidities, upper limb versus lower limb, etc.) to select the most appropriate measurement tool. Practitioners working with female patients experiencing lymphedema in the upper limb secondary to BC will have a stronger body of evidence-based outcome measures to select from (FACT-B+4, EORTC QLQ-BR23) (Coster et al., 2001; Oliveira et al., 2015; Patoo, et al., 2015). Practitioners should stay abreast of research developments surrounding this topic since the recent influx of promising lymphedema-specific measurements and cultural adaptations for these measures indicate that further psychometric testing is underway (Devoogdt et al., 2014; Launois et al., 2002; Oliveira et al., 2015; Viehoff et al., 2008). Program development that establishes protocols for selecting outcome measurements used during evaluation and assessment would be appropriate based on this critically-appraised topic. In conclusion, this critically-appraised topic supports the use of the DASH for patients with lymphedema when lymphedema is secondary to breast cancer. For patients with lymphedema not secondary to BC, this critically-appraised topic recommends adoption of the LLIS. Future program development is recommended to outline decision-making protocols for outcome measures that are awaiting further psychometric testing (Lymph-ICF, Lymph-ICF-LL, LyQLI, & ULL-27). Development of these protocols will allow all lymphedema patients within a setting to

be assessed with reliable and valid measures in a consistent manner. In addition, implementing these assessments in a systematic way will provide cohesion across therapists and settings and communicate intervention outcomes with a variety of disciplines along the continuum of care.

**Implications for Researchers:**

This critically-appraised topic has multiple implications for researchers. Due to the limited amount and types of research surrounding each lymphedema-specific measure, further research is needed to evaluate the psychometric properties of the LLIS, Lymph-ICF, Lymph-ICF-LL, LYMQOL, and ULL-27. Furthermore, there is a need for studies addressing the cultural adaptation and translation for these types of measures (Oliveira et al., 2015). Overall, it appears that generic measurements such as the SF-36 and DASH are reliable and valid for assessing HRQoL, and are often used as a comparison against newer measurement tools (Davies et al., 2015; Devoogdt et al., 2014; Launois et al., 2002; Viehoff et al., 2008, etc.). Through the use of well-studied generic tools, researchers should investigate the aforementioned lymphedema-specific measurements and encourage further development for distinct characteristics of HRQoL in patients with lymphedema. This will provide practitioners with measures that objectively demonstrate the effects of intervention as related to function during a time of utmost importance (Doucet, 2014).

**Bottom Line for Occupational Therapy Practice/ Recommendations for Better Practice:**

Occupational therapists specializing in lymphedema can apply information from this critically-appraised topic to better inform decisions when selecting outcome measures on a patient's HRQoL. Lymphedema-specific measurement devices are ideal for most accurately quantifying results of therapy (Launois et al., 2002), but many are still awaiting adequate psychometric backing for full implementation at this time. The DASH, a generic HRQoL measure that is widely used in practice, has demonstrated excellent reliability and validity on women with lymphedema secondary to BC (Davies et al., 2015). This critically-appraised topic implies that better practice in lymphedema therapy can be obtained by implementing this generic HRQoL for use with patients with BC. For patients who do not have lymphedema secondary to BC, it is recommended to use a lymphedema specific HRQoL measure to obtain a more specific and personalized picture of the impact that lymphedema has on the patient. Thus, for these purposes, the research indicates that the LLIS is currently the best route, excluding use with patients with BC for which the DASH would be a better assessment tool. These conclusions were reached after reviewing psychometric properties, ease of clinical use, and generalizability to populations in the U.S. With further testing in the U.S., the FACT B +4 could be a viable option for patients experiencing lymphedema secondary to BC. Further details on the data used to reach these recommendations are presented in Table 1.

**Involvement Plan**

In 2013, Medicare mandated that therapists report G-codes, a functional status code for patients across points of treatment. Our review, which revolved around evaluating psychometrically-sound measurement instruments used by lymphedema specialists to measure HRQoL, led to the recommendation of two assessments: the DASH and the LLIS. In deciding upon the best route to translate knowledge gained from our research, we met with Heidi Shaffer, our collaborating clinician for this project. The process for our involvement plan has been outlined in Table 2. We began our dialogue with Heidi around the fact that the Gig Harbor Lymphedema MultiCare clinic already purchased the LLIS, a lymphedema-specific measurement tool. In highlighting this fact to Heidi, we learned of current obstacles to full implementation of this assessment.

As Heidi explained, the LLIS G-code calculator was not embedded into Epic®, the EMR system used by MultiCare, making the assessment difficult to utilize. Currently, some therapists substitute this standardized assessment with their clinical reasoning and a G-code calculator independently created by MultiCare for reporting G-codes. Heidi indicated that the LLIS had been requested to be inputted into the computer system, but the request had not yet been implemented. Hence, even though the LLIS has its own G-code calculator, it was not readily available for all clinicians to use due to the fact that their computer system had not been updated. At this point in our conversation, Heidi pointed out that Sherri Olsen, Director of Physical Medicine and Rehabilitation, would be the appropriate person to talk to about our knowledge translation process to implement our recommendations. Related tasks and products for this meeting are detailed in Table 2, Items 1-2.

The other assessment recommended by our research was the DASH, a generic upper extremity HRQoL tool which does not come with its own G-code calculator. Heidi was excited about the idea of creating a G-code calculator for this assessment in order to promote its efficiency, but reiterated that we should meet with Sherri as a first step. Hence, we learned that we had an opportunity to introduce our knowledge translation plan to a person who could potentially facilitate a largescale change, but that a barrier existed in the process of embedding code into the Epic® computer system. This added a new dynamic to our knowledge translation process as we considered how to best present our research to Sherri to effect change, and how we might be involved with this third party of computer technicians.

Next, Heidi suggested we provide an in-service presentation and printed materials to MultiCare lymphedema therapists to describe administration of the DASH and the LLIS. She thought that outlining the pros



and cons for each assessment in addition to providing a pamphlet that therapists could quickly refer to would be helpful. These next task steps and products are elaborated upon in Table 2, Item 3.

Finally, we discussed the possibility of presenting our findings at an AOTA conference. To this end, Heidi recommended we also look into submitting our research to the National Lymphedema Network Conference scheduled for 2018. This last step is outlined in Table 2, Item 4.

As evident from our conversation with Heidi, there are contextual factors to our knowledge translation process that we had not previously accounted for. As clinical use of an assessment is largely dependent on its usability within an electronic documentation system, there are cultural, technical, and administrative factors not only within the MultiCare organization itself, but also within the Epic® organization to consider. We felt that if we were able to effect change on an organizational level by integrating the LLIS and DASH assessments into the documentation system, there would remain individual factors to analyze. Current practice of applying clinical reasoning to produce HRQoL descriptions and corresponding G-codes implies that an internal process exists that may be difficult to change. Thus, our knowledge translation may have been affected by the long held practices of the lymphedema therapists themselves, which is consistent with the ARC model for knowledge translation (as cited in Palinkas & Soydan 2012).

While these contextual factors presented possible barriers, they also provided valuable information to inform our strategy and planning process. Upon meeting with Sherri, we had planned to inquire as to how we could best aid in pushing Epic® to embed the two assessments and their corresponding G-code calculators into the computer system. During our in-service presentation and through distribution of printed materials, we demonstrated that adoption of the DASH and LLIS supports evidence-based practice and, each with its own G-code calculator, will aid in the efficiency of the practicing clinicians. If we pursue an application to the National Lymphedema Network conference and AOTA conference, we hope to further impart this knowledge translation to a wider audience. In terms of evaluating the outcomes of these various activities, we followed up with a satisfaction survey at the end of our in-service presentation.

### **Knowledge Translation Activities and Products**

The main goal of our knowledge translation process was to come ‘full circle’ by applying our evidence-based recommendations to G-codes for Medicare reporting, as this was a piece of the original research question from our collaborating clinician. Calculating accurate G-codes rests on the use of psychometrically sound

assessments, thus we felt G-codes would also be a logical avenue to bring about evidence-based change for the MultiCare lymphedema therapists. After meeting with Heidi on February 13, 2017 we learned that neither the LLIS nor the DASH were features of Epic®, the electronic medical records system used by MultiCare lymphedema therapists. To increase the ease in utilizing our recommended standardized assessments, we established a second goal for our knowledge translation process: to make these two assessments readily available within the Epic® system. After hearing about this proposal, Heidi recommended we meet with Sherri Olsen to discuss the process to bring about this change.

The first stage of our knowledge translation process aimed to create a G-code calculator for the two recommended assessments used to measure HRQoL for patients with lymphedema: the LLIS and the DASH. We learned that the LLIS has a G-code calculator embedded within its e-format, but clinicians at MultiCare did not have a readily available G-code calculator for the DASH. Upon researching G-code calculations, we quickly learned that G-code modifier “cheat sheets” had already been created for a variety of assessments. As the DASH produces a score on a 100 point scale and modifiers are coded in units of 10 from 1 to 100, converting DASH assessment scores to a G-code modifier score was more of a seamless process than we anticipated. We verified our findings, reproduced the calculations, and distributed small laminated copies of the DASH ‘cheat sheets’ for clinicians during our in-service presentation. This was the first product of our knowledge translation process.

During an in-service presentation held at Tacoma General Hospital, we spent about 30 minutes with eight practitioners highlighting our research and the take-aways from our findings. We prepared a PowerPoint presentation to aid us in explaining our research process, findings, and implications, but experienced technical difficulties in showing this during our presentation. As a result, we forwarded a copy of the PowerPoint presentation to Heidi and Sherri following the in-service. While conversing with the lymphedema therapists, we learned that standardized assessments are typically administered to patients on a laminated copy followed by the therapists’ entry of the scores into Epic®. We also learned that therapists often use the Quick DASH in lieu of the DASH, an assessment our research review did not cover. While these two unexpected hurdles arose during our in-service presentation, the therapists seemed very interested in the table we had created and very receptive to the information provided regarding the recommended assessments. A satisfaction survey was used to gauge the delivery and utility of the information presented. This in-service presentation, accompanying PowerPoint, and satisfaction survey served as the second piece of our knowledge translation process.

The final stage of knowledge translation for this research revolved around an hour long meeting with Sherri at the University of Puget Sound campus on April 14, 2017 with George Tomlin, our facilitating faculty member. We found this meeting to be integral for obtaining insight into the realities for practicing lymphedema therapists. Sherri described that a common barrier to accessing lymphedema therapy services often lies in the referral process from oncologists. She explained that doctors are often concerned about the load of appointments that their patients must attend and often do not always understand the role of occupational and physical therapy in addressing lymphedema at the critical juncture early on in their diagnosis. Often, she explained, patients do not experience lymphedema until weeks or even months after seeing their doctor, and thus lymphedema therapy does not become an immediate issue for them to address. Sherri explained her involvement in current research regarding “prehab” for lymphedema treatment, and the desire to provide hard evidence showing the benefits of therapy early on to doctors. She explained that our research concerning HRQoL for patients with lymphedema has aided her in the early process of her research to identify a HRQoL measure for use in her study. While this confirmed the utility in our research implications for other researchers, this meeting also revealed an unexpected difficulty to our knowledge translation process as related to the bigger picture that practitioners work in: if clients are not receiving therapy services until a more chronic stage in the course of their lymphedema, then an HRQoL is less likely to demonstrate changes in function along the course of therapy in the way that it likely would if patients were referred earlier in the course of lymphedema management. Overall, this could potentially lead to a smaller change in function as illustrated by G-code reporting when, in actuality, the lack of change is a result of the late referral to therapy. This meeting brought a new perspective to how our research, a piece of the puzzle that is the world of lymphedema therapy, exists in relation to larger systemic forces at play.

In addition to this insight, meeting with Sherri allowed us to follow up on our final goal of knowledge translation: to facilitate making the DASH and LLIS readily available within the Epic® system. Sherri suggested we craft an email with detailed instructions that she could forward to the infomatic specialists at Epic®. This email became the final step in our knowledge translation process. A remaining unforeseen difficulty in this process lies in not knowing if the Epic® computer programmers were successful in implementing our directions and if they were, how therapists understood or were informed about this new feature incorporated into Epic®. We also had not anticipated the amount of time and effort involved in preparing an email with explicit, detailed information to program the assessments into Epic®, and imparting a change to the way standardized assessments are administered

by lymphedema therapists. Effective knowledge translation requires not only communication amongst multiple parties for coordination purposes, but also education on processes (e.g. scoring the DASH, psychometric properties of each assessment, etc.) to ensure fidelity.

Additional pieces of our knowledge translation include submitting our findings to the 2018 AOTA conference next year, which we intend to complete in May when the AOTA submission guidelines become available. We located information about the National Lymphedema Network. However, we were unable to locate specific information regarding submission of research.

### **Knowledge Translations Outcomes**

At the end of our in-service presentation to the lymphedema therapists at MultiCare, we handed out a satisfaction survey to gauge the delivery and utility of the information presented on our research findings. The survey also provided the therapists an opportunity to reflect on their current practices and any barriers they may face in implementing our findings. In addition, we crafted an email with detailed instructions addressed to Sherri that she could forward onto the informatics specialists at Epic® that would allow the LLIS and the DASH along with their G-code calculators to be embedded into the computer system for ease of use. We plan to monitor the outcomes of this last piece of knowledge translation by remaining in contact with Sherri and Heidi via email in regards to progress of embedding these assessments into Epic®.

### **Knowledge Translation Effectiveness**

The purpose of our knowledge translation process was twofold: to inform clinicians of current evidence on lymphedema HRQoL assessments and to motivate change within the MultiCare organization towards using recommended assessments. An in-service presentation was the primary vehicle to enact both of these goals. For the second phase of our process, we used an active strategy of writing directions to be e-mailed to informatics specialists at Epic®. This was intended to promote change in current practices. Since this latter stage is still underway, we have not yet been able to evaluate the effectiveness of this change. In order to measure the effectiveness the first phase of the knowledge translation process, a satisfaction survey was implemented, the results of which informed our conclusions. .

The satisfaction survey was created for our in-service presentation to the MultiCare lymphedema specialists and was completed by six of the seven therapists who attended the presentation (one attended via conference call). The survey consisted of five quantitative statements using a Likert scale ranging from strongly agree to strongly

disagree and three qualitative questions. All of the respondents rated four of the five statements as strongly agree or agree. These statements included: (1) The information presented today was helpful for my clinical practice, (2) I understand the different situations for which the DASH and the LLIS are recommended, (4) I feel more informed about current research around lymphedema HRQoL assessments after this in-service, (5) The research process, results, and conclusions were clearly and professionally presented. The last three qualitative questions asked included: (6) Was there any information that was not covered for which you would have liked to know more about? (7) What barriers do you anticipate in implementing use of the LLIS or DASH? (8) Do you have any additional questions, comments, concerns, or suggestions related to this research? The results of this satisfaction survey provided a means for measuring the first phase of our knowledge translation process.

We were successful in some of our knowledge translation tasks and only partially effective in others. We met the objective of educating clinicians on psychometric data for HRQoL assessments. This was measured by items (2), (4), and (6) of the satisfaction survey which targeted the degree to which clinicians felt informed after the in-service presentation. All six respondents noted “agree” on (4) and (6) indicating that they felt more informed after participating in our in-service presentation. Item (6) was left blank on all surveys, signaling that clinicians did not feel there were gaps in the topics covered. Based on these results, we can conclude that we adequately informed clinicians and that data regarding psychometric standing of lymphedema HRQoL assessments was sufficiently translated.

The objective to motivate change within the MultiCare clinic was carried out through our in-service presentation, creation and delivery of G-code modifier “cheat sheets,” and by taking steps toward incorporating the recommended assessments into Epic®. The following items of the survey targeted this domain: (3) I plan to use the DASH with the G-code modifier card in clinical practice and item (7) What barriers do you anticipate in implementing use of the LLIS or DASH? Item (3) received one response of “strongly agree,” one response of “agree,” three “neutral,” and one response of “disagree.” Barriers listed in item (7) were “facial edema patients,” “time concerns,” “duration of session,” and “don’t use LLIS.” As the majority of clinicians felt neutral or disagreed with the statement regarding their intent to use the DASH and G-code modifier card, we concluded that most clinicians did not find the G-code modifier card useful and that they were unlikely to begin using the DASH if they were not already. Barriers listed surrounding the element of time in a therapy session and the types of diagnoses that the DASH and LLIS do not address further implied that our in-service presentation had not effectively considered

these important factors when making recommendations. The issue of time efficiency arose during a question and answer period during the in-service when a clinician inquired about research on the Quick DASH; an assessment we had not encountered in our search. Based on this feedback, we have concluded that we have not yet met our second objective in our knowledge translation for motivating change within MultiCare.

The goal to ignite change was elaborated on by composing an email to Epic® programmers about embedding a feature for scoring and calculating G-codes for the DASH and LLIS in the Epic® system. As this email has only recently been submitted, we plan to measure our effectiveness through follow up correspondence with Sherri. Specifically, we plan to inquire about a response from programmers, if clinicians are administering HRQoL assessments as recommended, and how clinicians will be informed of the new features in Epic®. These final stages will allow us to evaluate our impact on motivating an adoption of the DASH and LLIS at the MultiCare clinic.

It has been reported that there is often a gap lasting up to 20 years between establishing evidence and implementing or translating this knowledge into practice (as cited in Palinkas & Soydan, 2012). In order to address this issue and widen the audience to whom our research is intended, a final element of our process has been to submit our findings to AOTA for a poster presentation at their 2018 conference. For this step, we have drafted a submission proposal for our research. We plan to submit this around the time that the application period opens beginning May 1. Measuring effectiveness of this process will obviously take place at a future date and will likely involve a satisfaction or impact survey at the conference should the proposal be accepted. This final step will attempt to correct the issues we found to be ineffective during our in-service at MultiCare and will serve as an attempt to translate our knowledge on a larger scale.

### **Evaluation of Overall Process of Project**

The process of this critically appraised topic has been instrumental in building a sense of identity as occupational therapists. As the project occurred in tandem with our learning about occupational therapy via participation in an entry level master's degree program, this research project has provided a framework of the process involved to be an evidence-based practitioner. As we arrive towards the end of this journey, we are able to better reflect on this process.

We began with a research question that sought to understand the utility of G-codes in a lymphedema setting and were quickly discouraged by the initial search result of one article in the databases that used the words "G-codes" in a way that was relevant to occupational therapy. Upon meeting with our project chair who was an expert

on the content related to this topic, we were able to expand the way we conceptualized G-codes by focusing on the elements of function that G-codes were targeting. The guidance we received from our project chair during this phase led us to a new search strategy that operationalized G-codes via HRQoL assessments used in lymphedema therapy. This step enabled us to “cast a wider net” within our search strategy that was appropriate for critical analysis and tied back to our collaborating clinician’s initial question. In practice, this stage may represent an identification of a problem or need for further understanding around practice trends.

After identifying the most appropriate HRQoL assessments to include in our research, we dissected them for their reports of psychometric data to include in a CAT table format. This stage required us to consider and analyze the research practices involved in each study for a succinct report and overall evaluation. While it felt tedious and required meticulous attention to each article, the skills used during this phase will be required to independently access information as practitioners. This stage also required us to continually evaluate the relevance of articles in relation to our search criteria.

The final stage in this research project surrounding knowledge translation has allowed us to stand back and understand how our findings fit into the bigger, ‘real world’ picture of lymphedema therapy. Meeting with a team of lymphedema practitioners during our in-service presentation and then following up individually with Sherri Olsen has led us to understand emerging areas for research, barriers to implementing evidence-based practice, and how systemic factors such as the referral process to lymphedema therapy work to affect G-code scores. This stage was a valuable first experiment in learning how to bring research most efficiently into a practice setting. We learned that delivery needs to be engaging, motivating, and coordinated by thoughtful and efficient communication with multiple parties.

In all, this project has been an important element in our growth as it has armed us with the tools required and the firsthand knowledge needed to be evidence-based practitioners. While much of learning within an academic program revolves around individual enrichment and scholastic endeavor, this project allowed us to contribute to the field of occupational therapy as a whole as well as providing valuable education and artifacts to local community-based practitioners within a particular hospital organization. We hope to continue to give back to our profession and its stakeholders in similar ways throughout our career in the years to come.

**Recommendations for Future**

As noted previously in our recommendation for researchers, several lymphedema-specific assessments (Lymph-ICF, Lymph-ICF-LL, LYMQOL, & ULL-27) are still awaiting adequate psychometric backing for full implementation in the U.S. population at this time. It would be prudent to revisit the original research question in four to five years' time to determine whether there are changes to our current findings.

During our meeting with Sherri, future research needs were discussed including the possibility of identifying HRQoL assessments for patients with specific diagnoses like cancer. Applying the same research methodology and analysis used for this project could be applied to identify HRQoL assessments within a particular diagnostic population. Sherri noted that this information would be helpful evidence to justify use of specific HRQoL assessments. Furthermore, this could be instrumental in obtaining reliable outcome data for intervention research being conducted by MultiCare in collaboration with Seattle Cancer Care Alliance.

The research Sherri is currently pursuing addresses the efficacy of prehab, proactive habilitation prior to radiation and chemotherapy treatments, for patients undergoing cancer treatment. Within this discussion, it was also noted that additional research could be conducted regarding the benefits of prehab services for a variety of diagnostic populations. This research would be best completed through a systematic review of the literature looking at the potential outcomes resulting from this intervention, potentially including reduced hospitalization and insurance costs, increased patient satisfaction, and improved HRQoL.



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- “\*” before a reference indicates one that appears in the CAT table itself.

**Appendix A**

## Breast Cancer EDGE Task Force Rating Scale

(Adapted from StrokEDGE form)

Modification of Recommendation Scoring to be used with EDGE form submissions:

4 = highly recommended; the outcome has good psychometric properties and good clinical utility; the measure has been used in research on individuals with or post breast cancer.

3 = recommended; the outcome measure has good psychometric properties and good clinical utility; no published evidence that the measure has been applied to research on individuals with or post breast cancer.

2A = unable to recommend at this time; there is insufficient information to support a recommendation of this outcome measure; the measure has been used in research on individuals with or post breast cancer.

2B= unable to recommend at this time; there is insufficient information to support a recommendation of this outcome measure; no published evidence that the measure has been applied to research on individuals with or post breast cancer.

1 = not recommended; the outcome measure has poor psychometric properties and/or poor clinical utility.

Note: Reprinted from *Davies, C., Ryans, K., Levenhagen, K., & Perdomo, M. (2014). Breast cancer EDGE task force outcomes: Quality of life and functional outcome measures for secondary lymphedema in breast cancer survivors. Rehabilitation Oncology, 32, 7-12.*

## **Appendix B**

### **Access to Recommended Assessments**

Website to request access to the LLIS and G-code calculator:

- <http://klosetraining.com/llis-and-g-code-calculator/>

Website to download the DASH:

- <http://dash.iwh.on.ca/about-dash>

**Appendix C****G-code Modifier Card****G-code Modifiers****CN** (100 %) - 100**CM** (80-99%) - 80-99**CL** (60-79%) - 60 - 79**CK** (40-59%) - 40-59**CJ** (20-39%) - 20- 39**CI** (1-19%) - 1-19**CH** (0%) - 0**DASH SCORE****[(sum of n responses) - 1] x 25**

n

Appendix D

PowerPoint Content from In-Service Presentation

Lymphedema HRQoL Assessments

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By: Bonnie Blair OTS, Gina Dellino OTS & Jennifer Thomas OTS  
 Collaborating Clinician: Heidi Shaffer OTR/L MSM CLT-LANA

Which patient-reported outcome assessments are most valid and reliable in measuring health-related quality of life (HRQoL) in patients with lymphedema?

The Results

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<p>Assessments</p> <p>12 selected, 10 reviewed, and 2 recommended</p>	<p>Disability of Arm Shoulder and Hand (DASH)</p> <p>Lymphedema Life Impact Scale (LLIS)</p> <hr/>
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Take Aways...

The DASH and LLIS currently have the strongest psychometric data for use with patients with lymphedema in the USA.

The DASH is widely used in practice and has demonstrated excellent reliability and validity on women with EC.

Several HRQoL assessments are still awaiting adequate psychometric backing for full implementation at this time.

Practitioners should stay abreast of research developments surrounding this topic since there has been recent influx of promising lymphedema-specific measurements could.

DASH

---

Who has experience administering the DASH?

Thank you for your attention during this presentation!

If you have any further questions, feel free to contact us:

Bonnie Blair: [BELAIR@pugetsound.edu](mailto:BELAIR@pugetsound.edu)  
 Jennifer Thomas: [JETHOMAS@pugetsound.edu](mailto:JETHOMAS@pugetsound.edu)

**Appendix E**

**Satisfaction Survey**

Please circle the answer that best describes your feelings after this in-service presentation.

**1. The information presented today was helpful for my clinical practice.**

Strongly Agree   Agree   Neutral   Disagree   Strongly Disagree

**2. I understand the different situations for which the DASH and the LLIS are recommended.**

Strongly Agree   Agree   Neutral   Disagree   Strongly Disagree

**3. I plan to use the DASH with the G-code modifier card in clinical practice.**

Strongly Agree   Agree   Neutral   Disagree   Strongly Disagree

**4. I feel more informed about current research around lymphedema HRQoL assessments after this in-service.**

Strongly Agree   Agree   Neutral   Disagree   Strongly Disagree

**5. The research process, results, and conclusions were clearly and professionally presented.**

Strongly Agree   Agree   Neutral   Disagree   Strongly Disagree

**6. Was there any information that was not covered for which you would have liked to know more about?**

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**7. What barriers do you anticipate in implementing use of the LLIS or DASH?**

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**8. Do you have any additional questions, comments, concerns, or suggestions related to this research?**

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**Thank you!**



**Appendix F****Email to Sherri Olsen**

Dear Sherri,

Thank you for your time in meeting with us today. We so enjoyed the opportunity to sit down and talk with you.

With regards to our discussion about getting G-code calculations for the DASH and LLIS into the Epic® EMR system, here is what we recommend:

--

For the LLIS, include a place in Epic® for the therapist to enter:

1. The final score (0-68)
2. The number of questions answered (0-17)
3. Question #18 regarding infection occurrence requiring oral antibiotics or hospitalization (options are 0-4 times)
4. Using the calculations in the attached Excel spreadsheet, have Epic® perform a calculation to convert the final score and number of questions answered into a single correlating Medicare modifier to be inputted into the patient's record.

\*This in effect creates a G-code calculator directly into Epic®, bypassing the Excel spreadsheet G-code calculator that came attached with the LLIS.

For the DASH, include a place in Epic® for the therapist to enter:

1. The sum of responses (0-150)
2. The number of questions answered (n=0-30)
3. Have Epic® perform a calculation to convert the sum of responses and number of questions answered into a final score using the formula below.

Formula:

DASH Disability/Symptom Score =  $\left[\frac{\text{sum of } n \text{ responses}}{n} - 1\right] \times 25$ , where n is equal to the number of completed responses.

4. Then convert the final DASH disability score into a single correlating Medicare modifier to be inputted into the patient's record using the Medicare modifiers located in the attached Excel spreadsheet (e.g. 100% impairment (CN) correlates with a score of 100, 80% impairment (CM) correlates with a score of 80, etc.).

5. Please provide a note for therapists: there must be at least 27 out of 30 responses answered to complete the calculation.

Additionally, include a place for the therapist to enter the optional subtest scores for:

1. Work Module:

The sum of responses (0-20)

The number of questions answered (n=0-4)

## 2. Sports/Performing Arts Module:

The sum of responses (0-20)

The number of questions answered (n=0-4)

For both of the optional modules, the final score is calculated with the formula below.

Disability Score =  $\left[\frac{\text{sum of responses}}{4} - 1\right] \times 25$ , where n is equal to the number of completed responses.

\*Please provide a note for therapists that all 4 of the optional responses must be answered to be calculated for each subtest.

These calculations for both the LLIS and the DASH should be accessible for therapists to document in evaluation, progress, and discharge reports.

**Table 1. Overview of HRQOL Assessments Analyzed**

Assessment	Type of assessment						Areas Assessed	Psychometrics		Study		Clinical Utility		EDGE Task Force Rating *
	Lymph edema	Cancer	Breast Cancer	Generic	UE & LE	Only UE		Test-Retest Reliability	Internal Consistency	Studied in the U.S.?	Study Population	Time required	Available	
<b>DASH</b>				x		x	Social – Psychological – Physical functioning - Symptoms	ICC=0.92-0.97	$\alpha=0.92$ - $-0.97$	Y	N=144	5-10 min.	Free	4
<b>EORTC QLQ BR23</b>			x				Functional: body image and sexuality – Symptoms: arm, breast, systemic therapy side effects	Not tested	$\alpha=0.46$ - $-0.94$	Y	Dutch=70, Spanish=168, U.S.=158			Not rated
<b>FACT-B</b>			x				Physical well-being – Social/family well-being – Emotional well-being – Functional well-being	ICC=0.85	$\alpha=0.62$ - $-0.90$	Y	N=47 N=295	5-10 min.	Free	Not rated
<b>FACT-B+4</b>	x					x	Physical well-being – Social/family well-being – Emotional well-being – Functional well-being – Arm morbidity	ICC=0.97	$\alpha=0.83$ - $-0.88$	N	N=279 N=29	5-10 min.	Free	4
<b>FLIC</b>		X					Role – Sociability – Emotional – Current health – hardship – Nausea – Pain	Not tested	$\alpha=0.90$ - $-0.94$		N=489			Not rated

<b>LLIS</b>	x				X		Physical – Psychosocial – Functional concerns	ICC=0.94- 0.98	$\alpha=0.93$	Y	N=102	5-10 min.	Free	Not rated
<b>Lymph- ICF</b>	x					x	Function: physical, mental – Activity and participation limitations: household, mobility, life domains/ social life	ICC=0.93	$\alpha=0.92$	N	N=90	5 min.		2A
<b>Lymph- ICF-LL</b>	x				X		Function: physical, mental – Activity and participation limitations: general tasks/ household activities, mobility, life domains/ social life	ICC=0.93	$\alpha=0.82$ -0.97	N	N=50	5-10 min.		Not rated
<b>LYMQOL</b>	x				X		Functional – Appearance/body- image – Physical symptoms – Emotions/mood	ICC=0.80	$\alpha=0.80$ -0.89	N	U.K.= 209, Dutch= 60			1
<b>ULL-27</b>	x					x	Physical – Psychological – Social	ICC=0.70- 0.86	$\alpha=0.78$ -0.93	N	N=301 N=145	11 min.		2A

\*See Appendix A for EDGE Task Force Rating descriptions.

\*\*Other assessments that were not included in the table due to insufficient psychometric data:

SF-36

LYQLI

**Table 2: Tasks, Products, and Target Dates for Knowledge Translation**

Task/Product (1a-f above)	Deadline Date	Steps w/ Dates to achieve the final outcome
1. Create G-code Calculator for DASH	April 4 (Prior to meeting with Sherri)	<ul style="list-style-type: none"> <li>• Research G-code criteria (March 2)</li> <li>• Develop excel calculation sheet (March 23)</li> <li>• Compare results with LLIS calculator (April 4)</li> </ul>
2. Meet Independently with Sherri Olsen	Prior to April 19 <sup>th</sup> .	<ul style="list-style-type: none"> <li>• Email to set up meeting (March 15)</li> <li>• Meet with Heidi's boss, Sherri to present our research and new G-code calculator.</li> <li>• Advocate for having the calculator programmed into their Epic® documentation system.</li> </ul>
3. In-service with MultiCare Lymphedema Therapists	April 26th or May 3rd	<ul style="list-style-type: none"> <li>• Create a clinical reasoning guide for when to use the LLIS or DASH</li> <li>• Visual aid (PowerPoint) on our findings</li> <li>• Satisfaction survey following presentation (April 20)</li> </ul>
4. Submit to Nat'l Lymph. Network and/or AOTA 2018 conference	TBD	<ul style="list-style-type: none"> <li>• Research requirements and deadlines for application process (March 20)</li> <li>• Create an abstract of our research paper (April 10)</li> </ul>

**Table 3: Knowledge Translation Completion Timeline**

Knowledge Translation Item	Target Date	Completion Date	Notes
G-code Calculator for the DASH <ul style="list-style-type: none"> <li>• Research G-code criteria</li> <li>• Develop excel calculation sheet</li> <li>• Compare results with LLIS</li> </ul>	April 4, 2017 <ul style="list-style-type: none"> <li>• March 2, 2017</li> <li>• March 23, 2017</li> <li>• April 4, 2017</li> </ul>	March 26, 2017 <ul style="list-style-type: none"> <li>• March 10, 2017</li> <li>• N/A</li> <li>• N/A</li> </ul>	Created laminated G-code modifier card for DASH in replacement of a G-code calculator.
Meet independently with Sherri Olsen <ul style="list-style-type: none"> <li>• Email to set up meeting</li> </ul>	April 19, 2017 <ul style="list-style-type: none"> <li>• March 15, 2017</li> </ul>	April 14, 2017 <ul style="list-style-type: none"> <li>• March 6, 2017 &amp; March, 23, 2017</li> </ul>	Follow up email with directions to input assessments into Epic® delivered April 14, 2017.  Plans to remain in communication via email in regards to implementation status.
In-service for MultiCare Lymphedema Therapists <ul style="list-style-type: none"> <li>• Clinical reasoning guide</li> <li>• PowerPoint on findings</li> <li>• Satisfaction Survey</li> </ul>	April 26/May 3, 2017 <ul style="list-style-type: none"> <li>• April 20, 2017</li> <li>• April 20, 2017</li> <li>• April 20, 2017</li> </ul>	March 29, 2017 <ul style="list-style-type: none"> <li>• N/A</li> <li>• March 26, 2017</li> <li>• March 26, 2017</li> </ul>	Clinician reasoning delivered through oral communication during in-service.
Submit to present at 2018 conferences (AOTA 2018, NLN 2019) <ul style="list-style-type: none"> <li>• Research requirements</li> <li>• Create abstract</li> </ul>	TBD <ul style="list-style-type: none"> <li>• March 20, 2017</li> <li>• April 10, 2017</li> </ul>	TBD <ul style="list-style-type: none"> <li>• March 19, 2017</li> <li>• April 7, 2017</li> </ul>	Submission guidelines posted as of May 1, 2017 for AOTA 2018 conference.  No data found regarding National Lymphedema conference.

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Signature of MSOT Student

Name: Gina M. Dellino Date: \_\_\_\_\_

\_\_\_\_\_  
Signature of MSOT Student

Name: Jennifer E. Thomas Date: \_\_\_\_\_

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Signature of MSOT Student