

Introducing the Leg Lymphedema Complexity Score

Robyn Bjork and Heather Hettrick

The Leg Lymphedema Complexity Score (LLCS) is a joint effort through the International Lymphedema and Wound Training Institute (ILWTI) and Nova Southeastern University (NSU) to create a tool to assist clinicians in identifying the various contributing factors and complexities of patients presenting with lymphoedema and skin impairments. The goal is to help drive proper examination and differential diagnosis, treatment planning, as well as utilisation of proper resources. This article highlights the development of the LLCS and how it can be incorporated into clinical practice.

Need for Leg Lymphedema Complexity Score (LLCS) and integration of familiar components

The International Society of Lymphology's staging for lymphoedema is widely utilised and ranges from subclinical Stage 0 to Stage 3, which "encompasses lymphostatic elephantiasis where pitting can be absent and trophic skin changes, such as acanthosis, alterations in skin character and thickness, further deposition of fat and fibrosis, and warty overgrowths have developed" (Executive Committee, 2016). According to this system, a patient could have significant soft tissue changes without marked limb volume, be functionally independent, and yet be classified as Stage

3. In contrast, another patient might present with massive hypertrophy of oedematous soft tissue, sizeable limb volume, severely limited mobility and dependent activities of daily living (ADLs), yet still be classified as Stage 3 lymphoedema. Thus, the ISL staging alone does not represent the complexity of the lymphoedema nor reflect the extent of interventions needed from a clinical standpoint. In order to justify the need for intensive or extended lymphatic rehabilitation, a scoring system was needed to more accurately reflect the complexity of clinical management.

Dreyer et al (2002) developed a lymphoedema staging system for lymphatic filariasis based on characteristic features. It is a system with seven stages with defining characteristics that are easy to identify clinically and represent lymphoedema complexity. Many of the components of this seven-stage system were incorporated into the LLCS, and the ISL staging 1–3 is noted within LLCS fields.

The Lymphedema Life Impact Scale (LLIS) is an 18-item measure of physical, psychosocial, and functional impairments caused by lymphoedema (Weiss and Daniel, 2015). A series of questions helps quantify a patient's everyday quality of life. This valuable tool has been integrated as a separate domain of the LLCS, used with permission from author Jan Weiss.

LLCS development

The LLCS project was spearheaded and authored by Robyn Bjork of the International Lymphedema & Wound Training Institute (ILWTI), and Heather Hettrick of Nova Southeastern University. The authors collaborated with nine national and international professional organisations: the World Alliance for Wound & Lymphedema Care (WAWLC),

National Lymphedema Network (NLN), Lymphatic Education & Research Network (LE&RN), Canadian Lymphedema Framework (CLF), American Venous Forum (AVF), American Vein and Lymphatic Society (AVLS; formerly American College of Phlebology (ACP), Association for the Advancement of Wound Care (AAWC), International Lymphoedema Framework (ILF) and the Lipedema Foundation. The project was funded through an unrestricted educational grant from SIGVARIS GROUP.

Each Collaborating Organization (CO) chose 1–2 representatives to act as liaisons between the authors and the task force, leadership and members of the respective CO. The inaugural draft of the LLCS was developed by the authors and then sent to COs for review. Each draft of the LLCS was finetuned through feedback and edits from COs over the course of 2 years — September 2016 to June 2018 — arriving at a final consensus with version 10.

LLCS purpose

Initially, the LLCS was called the 'Leg Lymphedema Severity Score'. Early on, the name was changed to "Lymphedema Complexity Score" per CO advice, in order to avoid the pitfalls of the tool inadvertently becoming a measure of treatment outcomes by payor sources. The purpose of the LLCS is to evaluate the complexity of a patient's lymphoedema and functional impairments to help guide interventions, referrals, and the necessary duration and intensity of treatment. Some of the fields within the scoring tool will reflect improvement, however, several represent ongoing chronic conditions that present with ongoing challenges, or complexities of care. The LLCS provides a reflection of lymphoedema complexity at any given time

Robyn Bjork MPT, CWS, CLT-LANA, CLWT is Founder, President & Executive Director of Education, International Lymphedema & Wound Training Institute; Heather Hettrick PT, PhD, CWS, AAWC, CLT-LANA, CLWT, CORE is Professor, Department of Physical Therapy, Nova Southeastern University, Director of Wound Education, International Lymphedema & Wound Training Institute

and helps to guide a comprehensive plan of care.

The LLCS includes 12 domains we commonly consider with lower-extremity lymphoedema patients: comorbidities, limb volume, edema texture, scar tissue, skin integrity, skin appearance, fat disorders (Lipedema), BMI and body shape, mobility, ADLs, and pain/discomfort, and the Lymphedema Life Impact Scale (LLIS) quality of life measure. Each domain of the LLCS is rated from 0–4, 0 having no presentation or problem to 4 being the most complex.

LLCS In clinical practice

The LLCS tool was first released for a usability test in clinical practice at the 2017 National Lymphedema Network Conference on Saturday, October 14. A cohort of 10 physical and occupational therapists and assistants incorporated the LLCS into their patient evaluations. Survey results indicated that the LLCS took rehab professionals approximately 10 minutes to complete. Sample feedback included the LLCS was user friendly (strongly agree/agree), the tool captures the essential aspects and complications associated with lymphoedema (strongly agree), and the clinicians surveyed would use this tool in clinical practice (strongly agree/agree).

The authors recently completed a content validation study to ensure the domains and scores are accurately represented and measure what they are intended to measure. This validation study involved six CLWTs/CLTs from different lymphoedema clinics. At each clinic, the therapists used the LLCS on 2–3 new patients independent from one another. The scores between the therapists suggested strong interrater

reliability as well as sensitivity and specificity.

In a 2020 publication in the *Annals of Vascular Surgery*, Desai SS et al encoded most of the LLCS using natural language processing and machine learning from clinical notes into the EMR. According to the authors, this resulted in a streamlined application of the LLCS without the physicians directly filling out about 75% of the tool.

Dr. Mark Melin, MD, FACS, RPVI a vascular surgeon and the West Campus Medical Director of the Wound Healing Institute at MHealth Fairview (University of Minnesota) stated the following with respect to the utilisation of the LLCS in vascular practice: “Lymphoedema remains an enigma for the vast majority of medical care providers. A truly applicable, insightful, comparable, educational and validated tool for worthy data collection has now been developed in the form of the LLCS. The LLCS is a highly valuable measuring tool that can facilitate patient evaluation, improve diagnostic ability through its completeness in a 12-domain assessment and advance individual and demographic healthcare for those with cancer, non-cancer, venous and lipedema associated lymphoedema. Adoption and utilisation of the LLCS by providers on a routine basis is facilitated by being able to complete the assessment in under 5 minutes. If we were to capitalise on the regular and standardised adoption of the LLCS within our medical records, the potential to improve recognition of the completeness of disease status with accurate documentation would advance patient care and outcomes and could improve payor coverage by meeting all guidelines. Efforts at future research utilizing this advanced yet simplified scale

will positively impact the diverse group of lymphatic patients that we serve.”

Future direction of LLCS

The next steps are to create a user/partner guide to the LLCS. This will include pictures representing clinical presentations that are referred to in the LLCS domains along with suggested referrals, interventions, and algorithms of care associated with standards of practice for each domain. This user-guide will be created from input from the collaborating organisations to support evidence-based practice and the intent is for it to be a guide, not prescriptive.

Future plans also include development of an Upper Extremity Complexity Score (UECS), as well as a Head and Neck Complexity Score (HNCS) to assist clinicians and guide clinical practice for these specialty presentations. The LLCS (*Table 1*) is also available for free download at <https://www.ilwti.com/pages/lymphedema-complexity-score> and the authors encourage its use in clinical practice and research.

References

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Table 1. Leg Lymphedema Complexity Score (LLCS).

LEG LYMPHEDEMA COMPLEXITY SCORE & DESCRIPTION							
12 DOMAINS (A-L)		0 Nominal Complexity	1 Mild Complexity	2 Moderate Complexity	3 Severe Complexity	4 Extreme Complexity	Score: (0-4)
A	<p>Co-morbidities: <i>Refers to any co-presenting condition that impacts overall health.</i></p> <p><i>Examples are provided but not limited to these conditions.</i></p>	No Co-morbidities	1-2 Co-morbidities mild presentations or well controlled, without complications	3 Co-morbidities moderate presentation or fairly controlled, some minor associated complications	4 Co-morbidities or co-morbidities include one or more of the following: <ul style="list-style-type: none"> • DVT • mild to moderate PAD • history of cancer • autoimmune disorder • controlled, insulin dependent diabetes • controlled, compensated CHF • renal disease 	5 or more Co-morbidities or co-morbidities include (not limited to) one or more of the following: <ul style="list-style-type: none"> • active cancer • severe PAD • uncontrolled, insulin dependent diabetes • uncontrolled, uncompensated CHF • end stage renal disease 	
B	<p>Limb Edema <i>Score based on most complex or involved limb</i></p>	No Edema	<p>Mild edema</p> <ul style="list-style-type: none"> • feeling of fullness or heaviness at the end of the day • swelling resolves overnight when lying flat (Stage 1 Lymphoedema) 	<p>Moderate edema</p> <ul style="list-style-type: none"> • worsens throughout the day • does not resolve overnight • shallow folds or creases where base of fold is visible with range of motion (Stage 2 Lymphoedema) 	<p>Severe edema</p> <ul style="list-style-type: none"> • deep folds of <10cm depth • base of fold is not visible with range of motion (Stage 3 Lymphoedema) <p>If both limbs are severe, score as extreme (4)</p>	<p>Extreme edema</p> <ul style="list-style-type: none"> • deep base folds of 10 cm or more depth (Stage 3 Lymphoedema) 	
C	<p>Tissue Texture <i>Score based on most complex or involved limb</i></p>	<p>Normal</p> <ul style="list-style-type: none"> • elastic, supple, pliable 	<p>Softly Pitting</p> <ul style="list-style-type: none"> • soft, boggy, feels like dough • 1+ to 2+ pitting scale with 15 seconds or less rebound • no areas of fibrotic tissue 	<p>Soft Fibrotic</p> <ul style="list-style-type: none"> • <25% of affected extremity is fibrotic tissue • 3+ to 4+ pitting edema or >15 seconds rebound • skin thickened & difficult to pinch/tent (positive Stemmer's Sign) 	<p>Fibrotic</p> <ul style="list-style-type: none"> • 25-50% of affected extremity is fibrotic tissue • difficult to pit; >30 seconds rebound • skin thickened & difficult to pinch/tent (positive Stemmer's Sign) <p>If both limbs are severe, score as extreme (4)</p>	<p>Fibrotic & Non-Compressible</p> <ul style="list-style-type: none"> • > 50% of affected extremity is fibrotic tissue • or areas of hard crust or fibrotic tissue that are non-compressible • unable to pinch/tent skin (positive Stemmer's Sign) 	
D	<p>Scars <i>Score based on most complex or involved limb</i></p>	<p>No Scarring</p> <ul style="list-style-type: none"> • no scars on or near affected extremity 	<p>Minor Scarring</p> <ul style="list-style-type: none"> • thin, surgical scar on or near affected extremity • scar is pale, flat and pliable 	<p>Moderate Scarring</p> <ul style="list-style-type: none"> • scar tissue involves ≤10% of affected extremity • scar may be thick but remains flexible/mobile 	<p>Severe Scarring</p> <ul style="list-style-type: none"> • scar tissue involves >10% to ≤30% of affected extremity • and/or scar is inflexible/immobile in one or more areas • and/or scars impair major lymphatic pathways (medial thigh or knee, groin) or are circumferential <p>If both limbs are severe, score as extreme (4)</p>	<p>Extreme Scarring</p> <ul style="list-style-type: none"> • scar tissue involves ≥30% of affected extremity • and/or scar is inflexible/immobile in one or more areas and limits function/mobility 	

Table 1. Leg Lymphedema Complexity Score (LLCS) (Continued).

LEG LYMPHEDEMA COMPLEXITY SCORE & DESCRIPTION						
12 DOMAINS (A-L)	0 Nominal Complexity	1 Mild Complexity	2 Moderate Complexity	3 Severe Complexity	4 Extreme Complexity	Score: (0-4)
E Skin Integrity <i>Score based on most complex or involved limb</i>	Intact • no discernable skin changes	Intact with Skin Changes • hemosiderin staining • or mild redness due to chronic inflammatory process • no wetness or open lesions • no skin infection (i.e. fungal, cellulitis) in past 6 months	Not Intact, No Infection • moist areas between toes or skin folds • and/or intertriginous dermatitis • no skin infection (i.e. fungal, cellulitis) in past 6 months	Not Intact, Recent Infection • lymphorrhea, blistering, oozing, or areas of serous crust • and/or denudement, partial thickness wounds • no active skin infection • history of skin infection (i.e. fungal, cellulitis) in past 6 months If both limbs are severe, score as extreme (4)	Not Intact, Active Infection • full-thickness wounds • and/or active skin infection (i.e. fungal, cellulitis)	
F Skin Changes <i>Score based on most complex or involved limb</i>	Normal • healthy, smooth skin	Mild Skin Changes Presents with one or more of the following: • orange peel or cobblestone appearing skin (mild papillomatosis) • hyperkeratosis	Moderate Skin Changes Presents with one or more of the following: • soft nodules • dry, sandpaper-like mossy lesions • mild verrucous hyperplasia	Severe Skin Changes Presents with one or more of the following: • hard nodules or knobs • soft, mossy lesions that project from surface of the skin • moderate verrucous hyperplasia If both limbs are severe, score as extreme (4)	Extreme Skin Changes Presents with one or more of the following: • proliferation of knobs forming clusters • translucent, vesicular mossy lesions prone to rupture • elephantiasis nostras verrucosa	
G Fat Disorders (Lipedema)	None	Stage One • disproportionate pear shape • normal skin surface • leg somewhat larger or thicker than average • some edema during the day, usually resolves overnight	Stage Two • skin texture changes • fatty deposits around knees and thighs • legs begin to thicken and lose shape • skin is rubbery or spongy, feels nodular • edema can occur, does not resolve as easily	Stage Three • skin texture more like “orange peel” • fat nodules easier to detect • Lobular deformations around knees and thighs • Larger ankle folds noted • Swelling more consistent; does not resolve • Hardening of connective tissues	Stage Four • lipo-lymphedema develops • complex folds and ridges with persistent swelling • Large weight gain • Mobility may be affected • Skin harder and/or discolored • May have presence of lymphorrhea	
H BMI*	Normal BMI = 18.5–24.9	Overweight BMI = 25.0–29.9	Class 1 Obesity BMI = 30.0–34.9	Class 2 Obesity BMI = 35.0–39.9	Class 3 Obesity or Severe Obese BMI = 40.0 +	

Table 1. Leg Lymphedema Complexity Score (LLCS) (Continued).

LEG LYMPHEDEMA COMPLEXITY SCORE & DESCRIPTION							
12 DOMAINS (A-L)		0 Nominal Complexity	1 Mild Complexity	2 Moderate Complexity	3 Severe Complexity	4 Extreme Complexity	Score: (0-4)
I	Mobility	Independent Independent in bathing and dressing, including washing and drying edematous extremities, and donning and doffing appropriate footwear or compression therapy	Minimal Assistance Needs minimal assistance for bathing, dressing and hygiene, including washing and drying edematous extremities, and donning and doffing appropriate footwear or compression therapy	Moderate Assistance Needs moderate assistance for bathing, dressing and hygiene, including washing and drying edematous extremities, and donning and doffing appropriate footwear or compression therapy	Maximum Assistance Needs maximum assistance for bathing, dressing and hygiene, including washing and drying edematous extremities, and donning and doffing appropriate footwear or compression therapy	Dependent Dependent bathing, dressing and hygiene, including washing and drying edematous extremities, and donning and doffing appropriate footwear or compression therapy	
K	Pain/Discomfort-range over past two weeks	0	1-2	3-4	5-6	7 or greater	
L	Lymphedema Life Impact Scale (LLIS)	LLIS Score 0	LLIS Score 1-18	LLIS Score 19-36	LLIS Score 37-54	LLIS Score 55-72	
Leg Lymphedema Complexity Total Score							

*<https://www.cdc.gov/obesity/adult/defining.html>; https://www.nhlbi.nih.gov/health/educational/lose_wt/BMI/bmi_dis.htm **This is purposefully general as it is addressed in the LLIS. LLIS used with permission from Jan Weiss, granted March 13, 2017.

Interpretation	
Score	Complexity
1-12	Mild
13-24	Moderate
25-36	Severe
37-48	Extreme