

ABSTRACT BOOKLET

2021 National Lymphedema Conference

ABSTRACTS Advances in Lymphatic Surgery and Care

Friday, December 3, 2021 12:25 - 1:20pm

ORAL ABSTRACT PRESENTATIONS

- Vascular lymph node transfers: A systematic review
 - Presenting Author: Yehuda Chocron MD
- LVA and VLNT a single centre case series
 - o Presenting Author: Elisabeth Lorange MD
- The Utility of the Omentum as a VLNT donor site
 - Presenting Author: Yehuda Chocron MD
- Public perspectives on lymphedema surgery
 - o Presenting Author: Yasser Almadani MD
- Primary Care provider barriers to cancer-related lymphedema care
 - o Presenting Author: Nicola Smith MD, CM, CCFP

F4.2 Vascularized lymph node transfers: Systematic Review

Institution/Hospital or Clinic	McGill University Health Centre
Authors	Yehuda Chocron, Gabriel Bouhadana, Alain J. Azzi,
	Joshua Vorstenbosch
Status of your research	X Complete ☐ In progress ☐ Not applicable

Introduction

Vascularized lymph node transfers (VLNT) are being used with increasing frequency for the treatment of breast cancer-related lymphedema (BCRL). However, there is a lack of consensus in the surgical field as to which recipient site should be utilized. We therefore aim to assess the evidence comparing the wrist and axilla as recipient sites for VLNT in BCRL.

Methods

We conducted a systematic literature review to compare the wrist and axilla as recipient sites for VLNT in BCRL. Demographic data, as well as Circumference Reduction Rate (CRR), Excess Volume Reduction (EVR), post-operative decrease in infections per year, post-operative discontinuation of compression garments and overall pooled complication rate were extracted from included studies. These were compared through a meta-analysis.

Results

A total of 37 studies met the inclusion criteria for a total of 689 patients. VLNTs to the wrist and axilla resulted in a decrease in CRR of 42.1% and 51.5%, and a decrease in EVR of 35.6% and 48.8% respectively. However, our meta-analysis showed no significant differences between CRR or EVR, between wrist and axilla as recipient sites. Similarly, we found no differences in post-operative decrease in infections per year, post-operative discontinuation of compression garments and overall pooled complication rate.

Conclusions

These data suggest non-inferiority between the wrist and axilla as recipient sites for VLNT in the context of BCRL. In the absence of randomized, prospective data, we hope these results can be used as an evidence-based reference and facilitate future studies.

F4.3 Lymphaticovenous anastomosis and vascularized lymph node transfer for the treatment of lymphoedema—a single center case series

Institution/Hospital or Clinic	Université de Montréal/ Maisonneuve-Rosemont Hospital
Authors	Michelle Bonapace-Potvin, MD <u>; Elisabeth Lorange,</u> Marie-Pascale Tremblay-Champagne, MD, FRCSC
Status of your research	X Complete ☐ In progress ☐ Not applicable

Background

Lymphedema is a chronic and debilitating condition. This study aims to assess the efficacy, common complications, and good prognostic factors of patients who suffered from lymphedema treated with microsurgery techniques such as lymphaticovenular anastomosis (LVA) and vascularized lymph node transfer (VLNT).

Methods

We performed a retrospective analysis of a series of adult patients who were treated for lymphedema with LVA and/or VLNT between March 2018 and February 2020 at Maisonneuve-Rosemont Hospital. Eighteen limbs met inclusion criteria. The demographic information, localization, cause, and stage of lymphoedema were recorded. The severity of lymphatic dysfunction and presence of any potent lymphatic channels were assessed via indocyanine green lymphangiography. Patients with patent lymphatic ducts were offered LVA, whereas those with total obstruction were subjected to VLNT. Pre- and post-operative circumferential limb measurements, use of compression garments and post-operative complications were compared.

Results

Nine lymphedematous limbs underwent LVA, eight underwent VLNT and one both. Minimum follow up was 12 months. Pre-operatively, 83% of patients (15) wore compression garments daily. Post-operatively, all but three patients (83%) were able to cease daily compression garments. The average resultant volume with LVA and VLNT after an average of 1 year was 87,5% and 92.56% respectively (range 77.6-99.4% for LVA, 66.5-105.4% for VLNT). Forty-four percent of patients (8) reported episodes of recurrent cellulitis pre-operatively. Post-operatively, three of those patients (17%) reported episodes of cellulitis. No surgical or post-operative complications occurred.

Conclusion

Patients with lymphedema can benefit from microsurgery. The greatest effect of surgery is decreased dependance on daily compression garments to maintain a stable and reasonable limb volume. Almost all of our patients were able to cease daily compression garments. Reduction of limb circumference after one year was similar with LVA and VLNT. Episodes of cellulitis were significantly lower after intervention.

F4.3 The Utility of the Omentum as a Vascularized Lymph Node Transfer Donor Site

Institution/Hospital or Clinic	McGill University Health Centre
Authors	Yehuda Chocron, <u>Victor Kang,</u> Joshua Vorstenbosch
Status of your research	☐ Complete X In progress ☐ Not applicable

Introduction: Vascularized lymph node transfers (VLNT) are an emerging therapy for a select population of lymphedema patients. There are numerous available donor sites for VLNT including both visceral transfers from the omentum and peripheral sites such as the neck or groin. The omentum offers the added benefit of avoiding donor site lymphedema and we herein discuss its role for VLNT.

Body: The omentum benefits from a large surface area with a well- vascularized lymphatic network harboring both immunogenic and angiogenic properties. The omentum's rich vascular supply can also offer vascularized soft tissue in the setting of radiation. The flap can be divided to allow for both proximal and distal inset in the affected limb making it an extremely versatile flap. Its intra-abdominal location also prevents the development of donor site lymphedema as compared to peripheral donor sites. From a surgical perspective, it can be harvested in a minimally invasive fashion either laparoscopically or through small laparotomy incisions. The main drawback of the omentum is the need to access the abdominal cavity which can rarely result in secondary complications including bowel adhesions, incisional hernia, bowel obstruction and seromas. Other more rare complications such as pancreatitis have also been cited⁶. Outcomes in cohort studies including limb circumference, cellulitis and patient impact scores have been similar between both visceral sites such as the omentum and peripheral donor sites. In certain instances, such as in breast-cancer, it has been postulated that the omentum can reduce post radiation axillary scar burden which can further alleviate lymphedema.

Conclusion: The omentum is an extremely versatile option for VLNT without any risk for donor site lymphedema and has been shown to offer positive outcomes for lymphedema patients. Future prospective studies are required to further corroborate these findings and offer a better understanding of risk profiles.

F4.5 Public Perspectives on Lymphedema Surgery

Institution/Hospital or Clinic	McGill University Health Centre (MUHC)
Authors	<u>Yasser Almadani MD, MSc</u> , Henry Zhao BSc, Joshua Vorstenbosch MD, PhD, FRCSC
Status of your research	☐ Complete X In progress ☐ Not applicable

Introduction: Lymphedema is a chronic disease of impaired lymphatic drainage and is a cause of significant physical and psychosocial morbidity. It affects between 350,000 and 5 million individuals in the United States and is likely underreported due to poor identification and a paucity of studies. In the Western countries, lymphedema is most commonly secondary to oncologic surgeries or radiation of the breast or skin, with damage to lymph nodes. Despite the significant burden on individuals with lymphedema, it remains underrecognized and does not receive sufficient financial support. At present, there is no definitive cure, but surgical interventions provide promise. This study uses a survey-based framework to assess the general public's perceptions of lymphedema surgery. Altogether, this study aids in determining the feasibility of implementing improved support and public funding for lymphedema surgery.

Methods: A survey was developed and distributed to participants via the validated crowdsourcing tool, Amazon Mechanical Turk. Demographic, lymphedema surgery interest, perceptions of lymphedema, and survey comprehension questions were incorporated.

Results: Our preliminary data suggest the majority of the respondents to the pilot survey can correctly identify patients with lymphedema and rank their severity from least to most severe. Respondents confirmed that personal hygiene and ability to work were some of most important concerns to them. Our preliminary data also suggest respondents seriously consider undergoing surgical interventions if significant limb circumference reduction is possible. The least important factor for respondents when deciding on lymphedema surgery was increased costs.

Conclusion: This survey provides valuable new insight into the public perspectives of lymphedema and the desire to advocate for the adoption of lymphedema surgery in Canada as a potential treatment. This survey is part of an ongoing endeavour to gauge the public's perceptions of lymphedema surgery.

F4.6 Primary care provider barriers to cancer-related lymphedema care

Institution/Hospital or Clinic	McGill University
Authors	<u>Dr. Nicola Smith</u> , Dr. Genevieve Chaput
Status of your research	☐ Complete X In progress ☐ Not applicable

Context

Cancer-related lymphedema can adversely impact patients' functioning and overall quality of life. Early detection is key to prompt management and patient support. Primary care providers, in their healthy lifestyle promotion roles, prevention-driven interventions, and chronic disease management mandates are well-suited to care for patients afflicted with cancer-related lymphedema. Despite this, their current involvement in the management of patients with this chronic condition appears limited.

Objective

The aim of this study was to identify known barriers of cancer-related lymphedema management by primary care providers.

Design

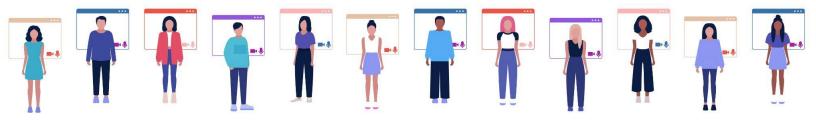
A scoping review of the literature was conducted in December 2020. Medline and EMBASE were searched for articles pertaining to primary care provider barriers in the identification and/or management of cancer-related lymphedema. The search included articles published up to November 30th, 2020, which were written in either English or French.

Results

Of the 114 articles, 34 were included. 4 main barrier themes were identified. The most reported barrier was lack of physician knowledge (n = 9). Other barriers included suboptimal communication between primary care and oncology specialists (n = 5), lack of physician comfort/confidence (n = 4), and poorly defined role of primary care providers in lymphedema care (n = 3).

Conclusions

Current evidence suggests primary care providers feel ill-prepared to care for patients with cancer-related lymphedema. As lymphedema is listed as one of the main late effects in the cancer survivorship domain, prompt identification and optimal management of this condition are of utmost importance. Further cancer-related lymphedema educational initiatives and dissemination of management resources are warranted to better support first-line providers in caring for this patient population.



2021 National Lymphedema Conference

ABSTRACTS Complex and Challenging Lymphedema

Friday, December 3, 2021 4:30 - 5:30pm

ORAL ABSTRACT PRESENTATIONS

- Management of head and neck cancer related lymphedema
 - o Presenting Author: Marize Ibrahim MSc, PT, CLT-LANA
- Deep central lymphatic dysfunction
 - o Presenting Author: Kelly Bell
- Obsessive compulsive disorder and body dysmorphic syndrome in lymphedema practice
 - Presenting Author: Anna Towers MDCM, FCFP

F8.4 Management of head and neck cancer related lymphedema

Institution/Hospital or Clinic	MUHC Lymphedema Clinic
Authors	Marize Ibrahim, Marie-Eve Letellier, Angela Yung,
	Georgina Cama, Genevieve Chaput, Anna Towers
Status of your research	X Complete ☐ In progress ☐ Not applicable

Context

Head and neck (H&N) lymphedema is a commonly neglected side effect affecting up to 50% of patients. Secondary lymphedema may develop externally, and/or internally, which may profoundly impact critical physical functions (e.g., breathing, swallowing, and eating). Current data surrounding use of head and neck night compression and its effect on lymphedema management is sparse.

Objective

The aim of this retrospective study was to assess whether compression therapy is helpful in the management of head and neck lymphedema.

Method

Retrospective analysis of H&N patients seen in a lymphedema clinic from January 2016 to September 2021. Paired t-test was used with different H&N measurements capturing the degree of lymphedema. Total neck circumference, right and left total facial composites, and tragus to tragus measures capturing degree of lymphedema, which was analyzed and compared over time. Management using compression garments were recorded and compared over time.

Results

Of the 102 head and neck patients, there were 71 males (69.6%) and 31 females (30.4%). With a total of 236 visits recorded, nearly half of the visits (43.2%) the patients did not require a prescription for compression garment, while 27.5% possessed a compression, almost half were wearing it daily while one third were not wearing it at all. Over the period of 12 to 24 months, most of the patients (67%) showed a reduction in all collected measures, with the majority not wearing or using any compression garment.

Conclusion

To date, little has been recorded on objectively measuring and recording head and neck lymphedema while comparing it to compression usage or not. Prior to setting up our database, information on lymphedema management was scarcely collected, limiting our retrospective analysis. Our analysis indicated that the majority of the patients showed a reduction in their head and neck lymphedema despite not using compression garments. Future research is warranted to establish if interventions other than compression therapy play a role in favorable H&N lymphedema outcomes, such as H&N exercises and/or self-massage.

F8.5 Urgent Need for Better Recognition & Effective Treatment of Deep Central Lymphatic Dysfunction

Institution/Hospital or Clinic	Central Coast Lymphedema Therapy
Authors	Leslyn Keith, <u>Kelly Bell</u>
Status of your research	☐ Complete ☐ In progress X Not applicable

Intro

Lymphedema is defined as lymph stasis with progressive reactive fibrosis that occurs anywhere in the body but is most often recognized when present peripherally. Optimal management of lymphedema requires maximizing decongestion centrally in both the deep and superficial systems. When conservative treatment of lymphedema fails, dysfunction of the deep central lymphatics should be considered and investigated as a possible cause.

Body

Injury and impairment of the deep central lymphatics may be falsely considered to be a rare condition. Impairment occurs due to congenital conditions, trunk/neck surgery, and abdominal cavity cancer treatments.² Without an understanding of deep lymphatic drainage patterns and the use of state-of-the-art imaging techniques, deep central lymphatic impairment may largely go undiagnosed.

We propose that deep central lymphatic injury-induced lymph stasis results in inflammation and fibrosis to the organs and not only negatively impacts organ function, but also the transport capacity of the entire lymphatic system.³ In the presence of deep central lymphatic impairment, traditional use of superficial anastomoses pathways to decongest peripheral edema will only be marginally successful.

Treatment must be guided by proper imaging to assess deep central lymphatic functioning and pathology. Patient subjective complaints, such as dyspnea, gastrointestinal distress, fatigue and pain, must be taken seriously. Blood test results may also be revealing for other complications of lymphatic dysfunction such as organ failure. Conservative treatment of deep central lymphatic impairment can include a carbohydrate-restricted diet, specialized deep breathing exercises, and a pneumatic pump. In some cases, surgical intervention may be indicated and highly effective.

Conclusion

Prolonged peri-organ lymph stasis combined with deep central lymphatic impairment leads to fibrosis, decreased organ function, and further lymphatic failure. Decongestion of peripheral lymphedema will be limited unless the deep central lymphatic impairment is addressed. Proper treatment is guided by accurate diagnosis through imaging.

References

- Michopoulos E, Papathanasiou G, Vasilopoulos G, et al. (2020) Effectiveness and Safety of Complete Decongestive Therapy of Phase I: A Lymphedema Treatment Study in the Greek Population. Cureus, 12(7):e9264. Published 2020 Jul 19. doi:10.7759/cureus.9264
- Dumont, AE. (1991) Thoracic Duct: Conditions Affecting function. Chapter in the book: Lymph Stasis: Pathophysiology, Diagnosis and Treatment, Waldemar L. Olszewski, Editor
- 3. Kataru, R. P., Wiser, I., Baik, et al. (2019). Fibrosis and secondary lymphedema: chicken or egg? Translational Research. doi:10.1016/j.trsl.2019.04.001
- 4. Maki, J. H., & Itkin, M. (2020). Central MR Lymphatic Imaging from the Bottom Up. Radiology, 295(2). doi:10.1148/radiol.2020200303

F8.6 Patients who overtreat themselves: obsessive compulsive disorder and body dysmorphic syndrome in lymphedema practice

Institution/Hospital or Clinic	Lymphedema Program, McGill University Health
	Centre, Montreal
Author	Anna Towers
Status of your research	☐ Complete ☐ In progress X Not applicable

Introduction

All seasoned lymphedema practitioners will have patients who seem obsessed with lymphedema compression, lymphatic drainage or exercise, at a level that is inappropriate to their condition and which in fact may cause harm. There is little literature on obsessive compulsive disorder (OCD) and body dysmorphic (BDS) syndrome as it relates to those with lymphedema.

Body

Following a brief overview of the psychiatric definitions of OCD and BDS, this composite case presentation will outline some characteristics of lymphedema patients who exhibit symptoms or signs of these disorders that impact their lymphedema care and their general health. Such patients, who usually have cancer-related lymphedema, may compulsively overtreat themselves with inappropriately high levels of compression, sometimes spending hours per day attending to their (often mild) lymphedema. They tend to be resistant to receiving guidance towards more appropriate management regimens.

Conclusion

This case presentation will initiate reflection and discussion on possible strategies that therapists might use in patients who present with a similar psychological portrait.



2021 National Lymphedema Conference

ABSTRACTS Advances in Outcome Measurement and Prevalence

Saturday, December 4, 2021 5:20 - 6:10pm

ORAL ABSTRACT PRESENTATIONS

- Exploring the Relationship among Lymphedema, Body Mass Index and Socioeconomic Status
 - o Presenting Author: David Keast MSc, MD, FCFP(LM)
- LYMPH-Q Upper Extremity Module A Rigorously Developed, Validated Patient-Reported Outcome Measure for Arm Lymphedema
 - o Presenting Author: Manraj Kaur PT, PhD
- Axillary Web Syndrome scoring system
 - o Presenting Author: Marie-Eve Letellier PhD, CDT
- A virtual arm self-measurement protocol to reduce development of chronic upper extremity lymphedema after surgery for breast cancer
 - Presenting Author: Kendra Zadravec PhD student
- Exploring challenges and creativity in self-managing breast cancer-related lymphedema and work by U.S. Hispanic/Latina survivors: A case study approach using photo-elicitation
 - Presenting Author: Elizabeth Anderson PhD, RN, CLT

S10.1 Exploring the Relationship among Lymphedema, Body Mass Index and Socioeconomic Status

Institution/Hospital or Clinic	Parkwood Institute
Authors	David H Keast MSc, MD, FCFP(LM), Ashrafunissa
	Janmohammad, MBBS, MSc, MPH, CCRP

Context

Over one million Canadians suffer from chronic edema/lymphedema. It is now known that there is no net absorption of tissue fluid by the capillary bed and that all excess tissue fluid is mobilized by the lymphatics. Accumulation of tissue fluid may result from absent, blocked or dysfunctional lymphatics. Risk factors such as cancer and related treatments, obesity, chronic venous disease and immobility are well known. In a previous study of 326 lymphedema patients, 45% had a body mass index of 30 or greater. However, little is known about the impact of socioeconomic factors on lymphedema. Socioeconomic factors include income, education and occupation.

Objectives

To conduct a preliminary study of the potential relationship between socioeconomic factors, body mass index and lymphedema

Design

An administrative database of patients with a main diagnosis of lymphedema for clinic attendance was reviewed. Deidentified data were collected. Statistics Canada 2016 census data for median household income by postal code were obtained. A subset of those with body mass index equal to or greater than 30 (Class I, II or III obesity) was also analysed. The first three figures of the postal code were extracted for all patients.

Setting

Parkwood institute Research

Patients

Records of lymphedema patients seen in the Parkwood Institute Wound and Lymphedema Clinic between 2011 and 2020

Results

A total of 728 patients were identified from 94 different postal codes. Of these 414 patients were from London Ontario. A subset of 337 patients had recorded BMI 30 or greater. Overall median household peaked at \$58,000 which is less than 2015 reported median household income for London of \$64,743. When obesity data are matched to income there is a cluster at lower incomes.

Conclusions

There is a possible association between lower socioeconomic status and lymphedema patients who have a comorbid factor of obesity.

S10.2 LYMPH-Q Upper Extremity Module – A Rigorously Developed, Validated Patient-Reported Outcome Measure for Arm Lymphedema

Institution/Hospital or Clinic	Brigham and Women's Hospital, Harvard Medical School, Boston, MA, United States and McMaster University, Hamilton, ON, Canada
Authors	Manraj Kaur (Brigham and Women's Hospital, Harvard Medical School, Boston MA, United Stated), Sylvie Cornacchi (Department of Pediatrics, McMaster University, Hamilton ON, Canada), Anne Klassen (Department of Pediatrics, McMaster University, Hamilton, ON, Canada), Louise Bordeleau (Department of Oncology, McMaster University/Juravinski Cancer Center, Hamilton, ON, Canada), Maureen Sawyer (Maureen Sawyer Physiotherapy, Hamilton, ON, Canada), Andrea Pusic (Brigham and Women's Hospital, Harvard Medical School, Boston, MA, United Stated)
Status of your research	X Complete X In progress ☐ Not applicable

Background: Breast-cancer-related lymphedema (BCRL) affects 14-21% of women post-cancer treatment and can have a substantial impact on health-related quality of life (HRQOL). Patient-reported outcome measures (PROMs) are a series of questions that assess how patients feel and function. To-date, a rigorously developed and validated PROM for arm lymphedema was lacking. To address this gap, we describe the development and ongoing work associated with the LYMPH-Q Upper Extremity (UE) module.

Methods: In-depth qualitative interviews were conducted with 15 women with BCRL in Canada and the US to elicit HRQOL issues. The interviews were coded line-by-line. Constant comparison was used to develop an item pool to develop 6 scales measuring arm symptoms, function, appearance, psychological function, and satisfaction with information and arm sleeves. These scales were reviewed by women with BCRL and clinician experts for relevance and comprehensiveness, then field-tested in 3222 women. Upon expert consultation, the need for scales measuring lymphedema worry, work impact and burden of conservative treatment was identified. New interviews were conducted, and the scales are currently being developed.

Results: A new sample of 12 women with arm lymphedema were interviewed. All women described lymphedema worry in terms of their experience (e.g., fear of worsening symptoms) and impact on usual activities (e.g., stopped certain chores). Most women reported making several accommodations to their workspace and work schedule (e.g., frequent breaks) but few reported stopping work. All women described the burden of ongoing symptom management (e.g., wearing/taking care of compression garments, exercise routine, and accessing community care) and the role of caregivers in symptom management.

Conclusion: Qualitative data confirmed the importance of the three concepts suggested by expert consultation. Next steps will involve the development and validation of the 3 new LYMPH-Q scales. The LYMPH-Q UE scales are available at no cost for research and clinical practice through www.qportfolio.org.

S10.3 Axillary Web Syndrome Scoring System

Institution/Hospital or Clinic	MUHC Lymphedema Clinic
Authors	Marie-Eve Letellier, <u>Marize</u> <u>Ibrahim</u> , Angela Yung,
	Anna Towers

Context

Axillary Web Syndrome (AWS) is a common and important complication of breast cancer axillary surgery. It is known to increase the risk of developing upper limb lymphedema. Approximately one third of patients will develop AWS, usually within the first 8 weeks post-surgery. Women self-report pain and demonstrate upper extremity range of motion (ROM) limitations and/or dysfunction, occasionally leading to postponement of radiotherapy. To our knowledge, there is no existing scoring system to objectively evaluate AWS and its progression over time.

Objective

To present a clinical scoring system developed to objectively assess AWS.

Setting

Three lymphedema therapists designed and developed the scoring system. Subsequently to test the assessment tool, two breast cancer survivors with an AWS and seven healthcare professionals (HP) from various disciplines, all of whom are certified lymphedema therapists, were invited to participate in a training and a testing of the scoring system.

Results

The two participants had different presentations: 1) AWS onset was a year post-surgery; no limitations reported, however impacting a little her quality of life (QoL). 2) AWS onset was post-radiotherapy; limitations present, impacting her QOL. Most (6/7) of the HP have over 5 years' experience in assessing and treating breast cancer patients. The intra-rater reliability was excellent, while inter-rater reliability ranged from good to very good. On debriefing, improvements to the original scoring system were elicited. Due to the COVID-19 pandemic, further testing of validity and reliability has been delayed.

Conclusion

To date, no scoring system exists to objectively score and triage the severity of AWS and prioritize rehabilitation needs. As resources are limited, the goal in developing an eventual valid and reliable AWS scoring system is to offer HP a systematic approach to track the severity and progression of this condition, facilitating optimum and timely patient care.

S10.4 A virtual arm self-measurement protocol to reduce development of chronic upper extremity lymphedema after surgery for breast cancer

Institution/Hospital or Clinic	University of British Columbia
Authors	K. Zadravec ^{1,2} , C. Singh ² , Bolette S. Rafn ³ , and K.L. Campbell ²
	¹ Rehabilitation Sciences Graduate Program, Faculty of Medicine, University of British Columbia, Vancouver, BC V6T 1Z3, Canada ² Department of Physical Therapy, University of British Columbia, Vancouver, BC V6T 1Z3, Canada ³ Cancer Survivorship and Treatment Late Effects Research Unit, Oncological Clinic at Rigshospitalet, Copenhagen, 2100, Denmark
Status of your research	☐ Complete X In progress ☐ Not applicable

Context

Prospective surveillance and proactive intervention can reduce the development and progression of lymphedema among women who have received treatment (e.g., surgery, radiation therapy) for breast cancer. Prior work from our group has shown women can measure their own arm circumference in a reliable and valid manner in both a lab and clinical setting using an inexpensive tape measure and video guide.

Objective

To evaluate patient feasibility and acceptability of this self-measurement protocol as part of ongoing virtual physiotherapy care at a public hospital in British Columbia, Canada.

Methods

The self-measurement package (tape measure, 10cm stir stick, links to online video guide) will be mailed to patients pre-surgery. At the 1, 6, and 12-month post-operative virtual physiotherapy visits, physiotherapists will complete usual standard of care, including reviewing self-measurements and asking patients to attend an in-person visit if there is an increase of ≥1cm at any measurement point and/or a change in subjective symptoms of lymphedema (i.e., heaviness). Women (n=50) who received unilateral/bilateral mastectomy/lumpectomy with or without axillary clearance, including those undergoing chemotherapy/radiation therapy, will be recruited. Participants will complete an online questionnaire (1, 6, and 12-months post-operative) about: (i) usefulness of self-measurement; (ii) ease and confidence performing self-measurement; and (iii) if self-measurement lessened any experiences of anxiety/worry. Participants will also complete patient-reported outcome measures of upper body function (Quick Disabilities of Arm, Shoulder, and Hand), health status (EuroQol Group EQ-5D-5L), and current mood/emotions (Hospital Anxiety and Depression Scale).

Results

Preliminary recruitment/outcome data will be reported.

Significance

Assessing the feasibility and acceptability of self-measurement can inform testing and implementing virtually delivered, self-managed care for breast cancer-related lymphedema on a larger scale. This work can improve delivery of physiotherapy services for breast cancer by overcoming well-identified accessibility barriers across Canada, such as geography and availability of trained physiotherapists.

S10.5 Exploring challenges and creativity in self-managing breast cancer-related lymphedema and work by U.S. Hispanic/Latina survivors: A case study approach using photo-elicitation.

Institution/Hospital or Clinic	University of Missouri-Columbia Sinclair School of Nursing
Authors:	Elizabeth A. Anderson, PhD, RN, CLT
	American Lymphedema Framework Project Postdoctoral
	Fellow - University of Missouri Sinclair School of Nursing
	S235 School of Nursing, Columbia, MO 65211
	Jane A. Armer, PhD, RN, FAAN, CLT, Professor Emeritus
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	S312 School of Nursing, Columbia, MO 65211
Status of your research	X Complete ☐ In progress ☐ Not applicable

Introduction

Research has shown that breast cancer-related lymphedema (BCRL), a chronic side effect of cancer treatment, can negatively impact the ability to perform work. BCRL changes work and life activities, necessitating adaptations in cultural, family, leisure, and occupational roles. Hispanic/Latina survivors are at greater risk of developing BCRL and may experience more complications, potentially compromising work ability. \

Aim

An ethnographic photo-elicitation case study explored the impact and changes Hispanic/Latina breast cancer survivors face while navigating (BCRL) self-management and work issues.

Method

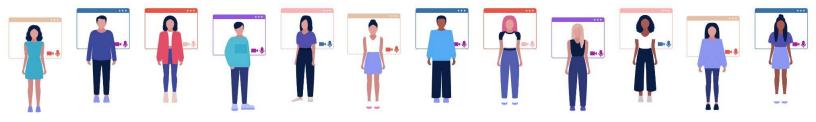
A qualitative study exploring the issue of BCRL self-management and work challenges was conducted. A photo-elicitation interview (PEI) built on the secondary analysis of a Hispanic/Latina multi-case return-to-work (RTW) study exploring the impact of BCRL on RTW quality of life. Qualitative descriptive and In Vivo coding were completed in the secondary data analysis, and Interpretative Engagement analysis was conducted on the PEI to identify impact and change themes.

Results

Secondary analysis of the RTW study illuminated themes of: importance of support relationships; family adaptation; and obstacles that Hispanic/Latina survivors encounter in self-managing BCRL and work activities. A photographic narrative illuminated daily challenges encountered as a cancer survivor self-managing and working with BCRL. With the help of family members, the participant implemented creative adaptations to complete work activities, care for her family, and continue to engage in social activities in her community.

Conclusions

A reciprocal relationship exists between BCRL self-management and work. This relationship requires creative ways to complete work and self-manage BCRL symptoms for life. Support of family, healthcare professionals, and work colleagues and adjustment of self-management behaviors to maximize work success optimizes quality of life. Optimizing survivorship care involves understanding cultural and personal views of work and social roles to effectively adapt BCRL self-management behaviors. Engaging with personal support networks can facilitate life-long self-management strategies.



2021 National Lymphedema Conference

ABSTRACTS - Poster Presentations

Be sure to visit the POSTER HALL during the conference to chat with the authors

1. Comparing the Effects of Various Scar Tissue Treatments on Lymphedema Volume: Two Case Studies

Presenting Author: Rebecca Wilkinson

2. The Role of MRI in Lymphedema: What Do We Know? **Presenting Author:** Mona M. Al Onazi

The Prevalence of Chronic Wounds in Persons with Chronic

Edema/Lymphedema

Presenting Author: David H Keast, Ashrafunissa Janmohammad

4. Quality of life of lymphedema patients: what affects it most?

Presenting Author: G Cama

5. ProLymph: a network for health professionals **Presenting Author:** Carol A Shay

- 7. CLF Pathways Celebrating 10 Years Anniversary of Educational Content **Presenting Author:** Anna Kennedy
- Think Outside of the Box: A Case Story!
 Presenting Author: Marie-Eve Letellier
- 9. Is Lipedema Resistant to All Diets? The Impact of a Protein-optimized Ketogenic Diet on Women with Lipedema

Presenting Author: Leslyn Keith

10. Hands-off learning for hands-on treatments: Considering online professional learning opportunities for chronic edema and lymphedema practice

Presenting Author: Naomi Dolgoy

11. Lymphedema Treatment Act

Presenting Author: Heather Ferguson

1. Comparing the Effects of Various Scar Tissue Treatments on Lymphedema Volume: Two Case Studies

Institution/Hospital or Clinic	RW Massage Therapy
Author	Rebecca Wilkinson, RMT, CDT
Status of your research	X Complete ☐ In progress ☐ Not applicable

Introduction

Surgical incisions causing scar tissue can impair lymphatic drainage, particularly across the scar.¹ Releasing scar tissue may play a role in lymphedema prevention and management.²³ As therapists, we learn to treat scar tissue as part of lymphedema management, but there are various techniques to select from. By finding the most effective method, therapists will experience better outcomes leading to better maintenance.

Objectives

This case study seeks to evaluate the effectiveness of various scar tissue treatment techniques on lymphedema volume. Two patients were selected for this case study based on lymphedema stability, regular and reliable maintenance appointments, and consistent garment wearing.

Process

Measurements were taken before and after manual lymphatic drainage (MLD) treatment. Treatment consisted of MLD in conjunction with Deep Oscillation and scar treatment techniques (thirty minutes MLD at 100Hz followed by 15 minutes of scar treatment followed by thirty minutes MLD at 13Hz). Scar tissue intervention techniques include kinesiology tape, basic hand techniques, HIVAMAT 200 scar protocol, cupping, myofascial release techniques and Dolphin Neurostim (MPS therapy). Patient One was treated every two weeks, and Patient Two was treated every four weeks at a private massage therapy clinic.

Results

Results showed that each patient had her best post-treatment results with different techniques. In addition, sustained results between treatments were also different for each patient and different from the best post-treatment measurements. Unfortunately, both patients experienced an increase in total percentage edema compared to initial measurements.

Conclusion

These results indicate that treating the scar tissue may actually increase lymphedema volume. Additionally, there may not be one technique that is best for all patients. Further study with a larger sample size may clarify these results. In the meantime, it is up to therapists to explore their skill set and find what works individually.

¹ Warren, Anne G. BA, Slavin, Sumner A. MD. Scar Lymphedema Fact or Fiction?. Annals of Plastic Surgery: July 2007 - Volume 59 - Issue 1 - p 41-45 doi: 10.1097/01.sap.0000258449.23979.3f

² Lu SR, Hong RB, Chou W, Hsiao PC. Role of physiotherapy and patient education in lymphedema control following breast cancer surgery. *Ther Clin Risk Manag.* 2015;11:319-327. Published 2015 Feb 25. doi:10.2147/TCRM.S77669

³ Granzow, J.W., Soderberg, J.M., Kaji, A.H. *et al.* Review of Current Surgical Treatments for Lymphedema. *Ann Surg Oncol* **21**, 1195–1201 (2014). https://doi.org/10.1245/s10434-014-3518-8

2. The Role of MRI in Lymphedema: What Do We Know?

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Institution/Hos	pital or Clinic	University of A	lberta	
Authors		Mona M Al On	azi, BScPT, MSc	, PhDc., Margaret L
		McNeely, PT, I	PhD.	
Status of your research		☐ Complete	☐ In progress	X Not applicable
Abstract Title	Abstract Title The Role of MRI in Lymphedema: What Do We Know?			

Background

The current methods used to quantify lymphedema in the clinical setting rely mainly on measurements of arm size and volume. Outcome measures such as circumferential tape measurements, perometry, or water displacement may be used to assess the relative volume of the affected arm and are usually compared to the unaffected arm. While providing information relative to the size and volume of the limb, these measures do not provide information on changes that may be occuring within the limb tissues. Magnetic resonance imaging (MRI) is a noninvasive and safe imaging method that allows visualization of tissue composition, and provides three-dimensional images that allow for the quantification of water, fat and lean tissue composition. MRI provides a quantitative measure of the lymphedema tissue characteristics that can inform treatment response.

Objectives

The aims of this session are to

- (i) explain the basic physics of MRI in lay terms;
- (ii) describe the potential role of the MRI in lymphedema diagnosis and staging;
- (iii) provide examples of MRI images of tissue changes associated with lymphedema;
- (iv) discuss the potential of MRI in lymphedema research and its clinical implications.

3. The Prevalence of Chronic Wounds in Persons with Chronic Edema/Lymphedema

Submitters full	name	David H. Keast	
Institution/Hos	pital or Clinic	Parkwood Institute	
Authors		David H Keast MSc, MD, FCFP(LM), Ashrafunissa	
		Janmohammad, MBBS, MSc, MPH, CCRP	
Status of your	ur research X Complete ☐ In progress ☐ Not applicable		
Abstract Title	The Prevalence of Chronic Wounds in Persons with Chronic		
	Edema/Lymphedema		

Context

Chronic edema/lymphedema and its relationship to chronic wounds particularly of the lower extremity is underrecognized and undertreated.

Objective

To determine the prevalence of wounds in persons with lymphedema.

Design

Databases both in Canada and internationally were reviewed including LIMPRINT (Lymphedema Impact and Prevalence International) as well as personally communicated information. Wound data and patient characteristics were extracted.

Setting

Studies reviewed involved acute care, long term care, community care, specialized lymphedema services and wound management clinics

Patients

Data involved a total of 21,253 patients in 11 countries who met the criteria of chronic edema lasting more than 3 months.

Result

Overall prevalence of wounds was 32.7%. Prevalence ranged from a low of 2.0% to a high 73.6%. The lower prevalence data were seen in specialized lymphedema services dealing primarily with patients post breast cancer surgery with upper extremity lymphedema. The highest prevalence was seen in community nursing services in patients with lower extremity lymphedema. These patients tended to be older and to have multiple co-morbid conditions. These conditions include obesity, chronic venous stasis disease, volume overload conditions such as congestive failure and reduced mobility.

Conclusions

Poorly recognized chronic edema/lymphedema is a significant factor in chronic non-healing wounds particularly in the lower extremity. Strategies to manage chronic edema/lymphedema will improve wound healing in these patients, improve quality of life and lead to decreased health care costs.

4. Quality of life of lymphedema patients: what affects it most?

Institution/Hospital or Clinic	¹ McGill University Health Centre, Montreal, QC ² Department of Family Medicine, Secondary Care and Oncology Departments, McGill University Health Centre, and McGill University, Montreal, QC
Authors	G Cama ¹ , G Chaput ² , A Towers ²
Status of your research	X Complete ☐ In progress ☐ Not applicable

Context

Cancer-related lymphedema (CRL) is a chronic condition that can occur due to cancer and its treatments Irrespective of cancer location and type, CRL afflicts many patients, and negatively impacts quality of life (QOL). Identifying variables that impact QOL most is imperative to guide clinical interventions.

Objective

The goal of this study was to identify which self-reported QOL domain is most important to CRL patients.

Design, setting and patients

This retrospective study analyzed LYMQOL questionnaire data of CRL patients evaluated between January 2016 and December 2020 in a lymphedema clinic in Montreal, Canada. The LYMQOL, a validated QOL tool, comprises four domains: *Symptoms, Appearance/body image, Function, Mood/Emotion.* Each domain item is scored using a Likert-type scale; overall QOL is assessed using a 0-10 scale. Of the 574 LYMQOL, 255 upper limb (UL) and 258 lower limb (LL) were included; others were excluded due to incomplete data. 84.6% were women; mean age was 61 years. To determine which domain impacts QOL most, multiple linear regression models were identified for UL and LL data, respectively (95% CI). The absolute value of the coefficient (C) for each independent variable (domain) indicated the effect size of that variable on QOL.

Results

UL model revealed: Mood/Emotion (C=-0.75; p < .001); Function (C=-0.63; p < .001); Symptoms (C=-0.59; p < .01); and Appearance/body image (C=-.27; p=.06). LL model showed: Mood/Emotion (C=-0.91; p < .001); Function (C=0.89; p < .001); Symptoms (C=-0.33; p=.08); Appearance/body image (C=-0.27; p=.29). In both UL and LL models, the Mood/Emotion domain had the most significant effect on QOL.

Conclusions

Mood/Emotion domain appears to have the most impact on QOL of CRL patients, yet psychosocial issues are not routinely screened for as part of lymphedema management. Further studies are warranted to implement distress screening, interventions and/or appropriate referrals, to better address psychosocial needs.

5. Joining Forces and Moving Forward with The Prolymph Network

Institution/Hospital or Clinic	Lymphedema Association of Quebec
Author	Carol A Shay
Status of your research	☐ Complete X In progress ☐ Not applicable

Context

Lymphedema is an often underestimated and misunderstood consequence of obesity, venous insufficiency, infection, surgical procedures as well as cancer related treatment. Finding tools to facilitate better understanding and treatment of this condition is crucial. ProLymph is a valuable addition to the toolbox.

Goal of ProLymph

To increase awareness and knowledge about lymphatic disease and its management by providing a virtual interactive platform among therapists, physicians, nurses and allied health professionals for peer-to-peer learning, dialogue and networking.

Structure of the ProLymph Platform

Discussion section

Members can pose their questions, present complex cases and share their practical solutions developed to meet the needs of their patients in both the community and hospital settings. All discussions are archived and searchable according to topic categories.

Library

ProLymph managers and participants may deposit reference documents, guides and research abstracts accessible to all.

Web links

Links to major national and international organizations are provided

Event Section

Notices of courses and conferences pertinent to lymphatic disease are displayed

Conclusion

ProLymph is a timely and important additional resource for health professionals working with Lymphatic disease, using a technology that provides a free, safe, and secure environment with strong user identity verification via membership.

6. Developing a Canadian Clinical Practice Guideline for best-practice management of Breast Cancer Related Lymphedema

Institution/Hospital or Clinic	University of Alberta
Authors	McNeely ML, Harris SR, Dolgoy N, Al Onazi M, Parkinson J, Radke L, Kostaras X, Dennett E, Ryan JA, Dalzell M, Kennedy A, Capozzi L, Towers A, Campbell KL4 Binkley J, King K, Keast D.
Status of your research	☐ Complete X In progress ☐ Not applicable

Background: Breast Cancer Related Lymphedema (BCRL) is a significant swelling of the arm, breast and chest wall that occurs on the side of the breast cancer, and is one of the more frequent complications following treatment for breast cancer. A Clinical Practice Guideline (CPG) offers recommendations on the prevention, diagnosis and treatment of a specific condition. The aim of this work is to provide an updated BCRL CPG for a Canadian healthcare context.

Methods: The objective of the CPG is to provide information and recommendations for patients and their physicians when making decisions about diagnosis, risk reduction practices, and long-term management of BCRL. Using a patient-oriented research approach, the focus of the CPG will be on self-management, and the positive health model will inform guideline development. The Appraisal of Guideline Research and Evaluation II (AGREE II) instrument will be used; literature will be appraised by evaluating: 1) existing guidelines from other countries and regions, 2) evidence from systematic reviews and meta-analyses, and 3) direct evidence from clinical studies. A modified Delphi process will be used to inform decisions. Competing interests will be managed according to Guideline International Network principles. Recommendations will be presented using an actionable statement format, and will be linked to the level of evidence along with any relevant discussion or considerations used when informing recommendations. A draft of the guideline will be produced by the Steering Committee, then sent out to international experts and stakeholder groups for feedback.

Interpretation: Dissemination of findings will be shared at both national and international level conferences, through webinars, and a series of videos will be hosted on the websites of the Oncology Division of the Canadian Physiotherapy Association, and the Canadian Lymphedema Framework in both official languages.

7. CLF Pathways - celebrating 10 years anniversary of educational content

Institution/Hospital or Clinic	Canadian Lymphedema Framework	
Authors	Anna Kennedy, David Keast, Anna Towers,	
	Lori Radke, Mei Fu, Pamela Hodgson, Mei Fu	
Status of your research	☐ Complete ☐ In progress X Not	
	applicable	

Introduction

As part of the 2009 Stakeholder Meeting in the formation of the Canadian Lymphedema Framework, three pillars were identified as key priorities in advancing lymphedema care in Canada: Research, Education and Partnerships. A formal CLF 2011 study entitled Lymphedema Landscape reinforced the need for increased education and awareness of lymphedema.

Context

Although there has been a big influx of information about lymphedema available on the internet over the past 10 years, credible information that has been vetted by scientific experts and from trusted sources is still lacking. One of the first goals of the CLF was to create a national magazine that would address both patients living with lymphedema and the health professionals who support their care.

Process

This full-colour national magazine is targeted at a diverse group of lymphedema stakeholders: patients and caregivers, clinicians, product distributors and fitters, researchers, educators, policy advisors and community organizations.

Content

Canadian and International experts contribute evidence based material for regular columns including Clinical Perspectives, Research Advances, Medical Updates, Case Studies, Patient Perspectives, Ask the Expert, and Resources. A detailed repository of archived articles, listing by topic and author is available to health professionals via the HP Toolkit. Many articles topics also enhance the content of the CLF website.

Conclusion

Pathways has now celebrated 10 years of publication. The magazine has also provided the CLF with a sustainable revenue source to support its annual operating and project related costs. It takes a village to create the magazine and the success of Pathways comes from the incredible support of sponsors, advertisers, contributing authors, editorial board, publishing company, volunteers and of course, the provincial lymphedema associations in disseminating the magazine to their membership. A recent Heritage Grant from the Canadian Government will also help grow the magazine. We look forward to the next ten years!

8. Think Outside of the Box: A Case Story!

Institution/Hospital or Clinic	MUHC Lymphedema Clinic
Author	Marie-Eve Letellier

Context

As healthcare professionals (HPs), we are often in the search of ideas and solutions to help our lymphedema clientele. Even if we read and become educational resources to our patients, most of the time, our lymphedema management learning comes from them. The pandemic has changed how we do things... for both patients and HPs. This videoconference with a polite gentleman who openly shared his story was an eye opener and led to some shared lighter moments...

Setting

M. X. was 58 years old when he was diagnosed with oral cavity cancer (01-2018). He was treated with surgery, chemotherapy and radiation therapy. He was referred to our Lymphedema Clinic with mild facial and right neck edema. He had a severe trismus, so opening his mouth was a problem.

Since 03-2019, M. X. managed his lymphedema by being followed regularly by a lymphedema therapist for manual lymphatic drainage (MLD) and doing his own daily neck stretching combined with self-MLD. With the arrival of the pandemic, he had to revise his management as everything closed for a period and it was no longer possible for his therapist to perform intra-oral MLD.

As a child, M. X. had been taught by his parents to think outside of the box and to be creative... Therefore, he went to the sex store! To help him with his mouth opening, he bought the largest-head vibrator for the outside of his cheek and the smallest for the inside of his oral cavity.

Conclusion

The first conclusion regarding that videoconference was that it was an occasion for shared laughter! Then, it was a shared experience with the whole HP team and now we share this tip to other head and neck lymphedema patients. Just to say... what's in the box can have a second life or a first life with another purpose!

9. Is Lipedema Resistant to All Diets? The Impact of a Protein-optimized Ketogenic Diet on Women with Lipedema

Institution/Hospital or Clinic	Centre for vascular medicine, Hamburg,	
	Germany	
Authors	Gabriele Faerber, MD-PhD, Leslyn Keith, OTD,	
	OTR/L, CLT-LANA	
Status of your research	X Complete ☐ In progress ☐ Not applicable	

Intro

Lipedema is a fat disorder distinguished by a disproportionate lower body fat accumulation, hypersensitivity and pain, swelling, bruising with minimal trauma, and apparent resistance to traditional diet and exercise regimens. Up to 85-88% of patients with lipedema may have a comorbidity of obesity. Obesity can exacerbate lipedema symptoms and is associated with further health complications. A ketogenic diet has been shown to address obesity without inducing sarcopenia. In the two investigative trials described, the objective was to determine if symptoms of lipedema would also be resistant to a protein-optimized ketogenic diet or if positive outcomes could be realized.

Body

The intervention in both investigations was a protein-optimized ketogenic diet. In the first, a retrospective analysis was performed using a telephone survey with 58 patients with lipedema. The second study analyzed pre- and post-intervention measurements of 92 patients with lipedema or lipedema with secondary lymphedema, comparing two groups: nutrition therapy only (Group A, n=50) and nutrition with additional physical treatment (Group B, n=42). Results from the telephone interview included persistent pain reduction in 82.7% of participants, 24.5% had a reduced need for MLD treatments and 24.8% were able to use compression garments with reduced intensity. Measurement analysis showed no statistically significant difference between Group A compared to Group B.

Conclusion

Symptoms improved in over 80% of participants. Positive outcomes included pain reduction, decreased frequency/intensity of MLD and compression, reduced leg measurements and reduction in the distance between the ankles. Outcomes were not affected by the addition of physical treatments. These findings show that symptoms of lipedema are responsive to a protein-optimized ketogenic diet, indicating this intervention should be offered as part of comprehensive treatment for lipedema.

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10. Hands-off learning for hands-on treatments: Considering online professional learning opportunities for chronic edema and lymphedema practice

Institution/Hospital or Clinic	University of Alberta
Authors	N. Dolgoy, M.L. McNeely, C. MacLellan, S. Drefs, B.
	Martin, A. Kennedy, D. Keast.
Status of your research	☐ Complete X In progress ☐ Not applicable

CONTEXT: Distance and self-paced learning opportunities are increasing in healthcare education. Research shows benefits of technology-based educational programming. However, for lymphedema education, hands-on learning is a critical part of skill building; competency in lymphedema management requires a combination of foundational knowledge and practical experience.

As part of a MITACS Accelerate grant funded initiative between the University of Alberta and the Canadian Lymphedema Framework, a self-paced six-week e-learning course was offered to healthcare professionals and students. The e-course—Lymphedema and Chronic Edema Management—followed the trajectory of lymphedema across the lifespan, and included expert lectures on topics ranging from emerging research to clinical practice.

The e-course modules were designed to address various learning styles and strategies to maximize knowledge mobilization. Rather than transplanting existing in-person coursework into a digital platform, the e-course was structured for technology-based learning, addressing foundational aspects of lymphedema education. E-course development involved creating shorter interactive content delivery, self-managed knowledge checks, and tailored assignments addressing individualized learning goals.

RESULTS: The e-course was piloted in May-June 2021 with 35 healthcare professional learners (participants). Participant outcomes were collected through feedback, surveys (open and closed questions), and Likert scales. E-course outcomes were collected through assignments, and through the platform metrics including time spent on each module. Resource allocation was also measured. The preliminary data indicates positive self-reported outcomes from participants, and feasibility in terms of content, costs and delivery.

CONCLUSION: E-learning offers an opportunity for accessible lymphedema and chronic edema learning and foundational skill development for healthcare professionals.

OBJECTIVES: This poster session will review the development, delivery, and outcomes of the e-course. There will be focus on technology assisted learning and knowledge mobilization opportunities in lymphedema professional education. This session will discuss barriers and facilitators of lymphedema e-learning, with the intention of progressing more effective and efficient educational opportunities.

11. Lymphedema Treatment Act

Institution/Hospital or Clinic	Lymphedema Advocacy Group
Authors	Heather Ferguson, Deborah Crow, Judy Woodward
Status of your research	☐ Complete ☐ In progress X Not applicable

On this poster, the authors review the history and ongoing work of the Lymphedema Advocacy Group (LAG), an all-volunteer grassroots advocacy organization in the United States, comprised of patients, caregivers, healthcare professionals, and industry partners. Their mission is to advance care through improved insurance coverage for lymphedema compression supplies. LAG leads and supports efforts at both the state and federal levels, and their members have already succeeded in passing laws in several states, but the group's primary focus is the passage of the federal Lymphedema Treatment Act (LTA), an active bill in the United States Congress.

The poster begins with Executive Director Heather Ferguson and her discovery of the gap in insurance coverage for compression garments for her child with primary lymphedema, and how that led to her founding of the group and their legislative efforts. The story of inception is followed by a timeline of the critical steps in the group's 11-year journey of building a nationwide grassroots effort, learning to navigate the American legislative system, and the progress of the bill through to the present time. Although further work remains, the group has taken a little-known disease and turned it into the most broadly supported healthcare bill in the United States Congress.

The authors outline the effective advocacy strategies instituted by the group including informal and formal organizational steps, networking and coalition building, training and activating advocates, utilizing technology to enable advocates, communicating with legislators and their staff, and assimilation of recently published research findings to support improvements to patient care, and how that will translate into an overall reduction in lymphedema-related healthcare spending. Example products and photographs are included. The authors hope that the successful strategies presented in this poster can serve as a blueprint to guide and assist other groups in affecting positive change in their communities.