



National Lymphedema Conference

Celebrating a decade of partnerships and engagement with the lymphedema community

Toronto Airport Marriott Hotel • November 1–2, 2019



Abstract Session: RESEARCH – Friday, October 1, 4:00pm – 5:15pm

Moderator: A. Towers

Title: Is decreased functional capacity linked to balance in individuals with lower-limb lymphedema?

Authors: A. Marshall¹, M. Wright¹, A. Towers², R. D. Kilgour^{1,3,4}, N. St-Onge^{1,4,5,*}

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Context: Lower-limb lymphedema can impact functional capacity and possibly balance.

Objective: This study was designed to determine the effect that lower-limb lymphedema has on physical fitness and balance by examining a number of centre of pressure (COP) variables, such as mean velocity, root-mean-square (RMS) displacement, RMS velocity, and absolute position.

Design: The participants stood quietly on a Matscan pressure mat for five trials of 60 seconds each. Balance was assessed by analyzing the position and movement of the COP. Additionally, fall risk was assessed using the Berg Balance Scale (BBS) and measures on physical fitness were obtained using the Human Activity Profile (HAP) questionnaire.

Setting: Ten women (53.0 ± 9.3 yrs) with either primary or secondary lower-limb lymphedema and ten controls (50.8 ± 9.5 yrs) participated to this study. Women with lower-limb lymphedema were recruited from the McGill Lymphedema Research Program while age- and BMI-matched controls were recruited from the Montreal community. Exclusion criteria for both groups included: major visual or vestibular impairments, musculoskeletal deficits, and neurological disorders.

Results: Balance measures obtained from the Matscan were non-significant ($p > 0.05$) between groups. However, when considering each limb separately, RMS velocity values were larger for the limb affected by lymphedema (22.1% more than unaffected limb) possibly indicating a reduced ability to maintain balance on the affected side in individuals with lymphedema. Results also demonstrated significant lower physical fitness measures in individuals with lower-limb lymphedema ($p < 0.05$). However, fall risk was not different between groups ($p > 0.05$).

Conclusions: Factors affecting functionality in individuals with lower-limb lymphedema could be linked to their reduced ability to maintain balance on the affected side. Future research should focus on examining the effectiveness of specific interventions to improve balance on the affected side.

Title: A global perspective of gene dysregulation in lymphedema reveals potential therapeutic targets

Authors: Jennifer Yin Yee Kwan MD¹, Jeffrey P. Bruce PhD¹, Wei Shi MD¹, Benjamin Haibe-Kains PhD², Kenneth Yip PhD¹, [FEI-FEI LIUMD FRCPC](#)¹

¹Radiation Medicine Program, Princess Margaret Cancer Centre, Toronto, Canada

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Context: In developed countries, lymphedema is a major side effect of cancer treatments, affecting up to 1 in 5 patients. Lymphedema has been described as a combination of several pathologies (e.g. inflammation, fibrosis, adipose deposition). Lack of clarity on the relative importance of each of these pathologies has hindered drug development and precise targeting of treatments to the most relevant pathologies in this disease.

Objective: This project aims to utilize global temporal transcriptomic profiling to uncover the top biologically-relevant pathologies that occur during the course of this disease for therapeutic intervention.

Design: A lymphedema model was created by micro-surgically severing superficial and deep lymphatics in the tail of C57Bl/6 mice. The lymphedema model was validated for 4 parameters consistent with human lymphedema: 1) lack of lymph transport using a fluorescent tracer; 2) edema using volumetric measurements; 3) subcutaneous adipose layer expansion with hematoxylin and eosin staining; and 4) fibrosis with trichrome staining (n≥3 per time point). Affected tail tissue was collected at 0, 2, and 4 weeks after induction of lymphedema for temporal genome-wide transcriptome profiling (n=3 per time-point; Illumina HiSeq2500). Differential expression analysis combined with hierarchical clustering of significantly altered genes was used to identify the top pathologies. Validation of transcriptomic changes was completed with PCR.

Results: The mouse model exhibited qualitative absence of lymph flow, increased edema (p<0.001), increased subcutaneous adipose deposition (p<0.05), and increased fibrosis (p<0.05) compared to baseline over the course of 4 weeks. Transcriptomic profiling revealed two top pathological clusters involving: 1) down regulation of lipid metabolism and 2) up regulation of immune responses (FDR<0.05). Associated gene pathways were validated with PCR.

Conclusions: A model of lymphedema has been established that has been validated for 4 parameters consistent with human lymphedema. Top dysregulated gene pathways revealed on global transcriptomic profiling may be promising drug targets.

Title: Are differences in handgrip strength related to skeletal muscle thickness between healthy women and those with breast cancer-related lymphedema?

Authors: J. Whyte^{1,2,3}, S. Fallone^{1,2,3}, H. Hashemi^{4,6}, A. Towers^{1,2}, M. Boily⁷, L. Rosenthal⁷, H. Rivaz^{4,5}, R. D. Kilgour^{1,2,3,5}

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Context: Breast cancer-related lymphedema (BCRL) has been shown to alter skin and subcutaneous fat thickness; however, little is known about changes in skeletal muscle thickness and its effect on handgrip strength (HGS) in the lymphedemic arm.

Objective: Using ultrasound imaging to detect differences in tissue thicknesses and handgrip dynamometry to measure forearm strength, we set out to determine if there was a relationship between muscle thickness and forearm muscle strength between the lymphedema group (LG) and healthy control group (CG).

Design: Differences in thicknesses and HGS between groups were analyzed using paired t-tests.

Setting: All data were collected at the McGill Lymphedema Research Program Clinic of the MUHC.

Participants: LG participants had been diagnosed with stage 2, unilateral BCRL in the maintenance stage; whereas, the CG had no history of cancer or inflammatory disease. Each group consisted of twenty participants.

Methods: Using B-mode ultrasound, we recorded the raw radio-frequency (RF) data from 2 locations on the forearm of the affected and unaffected arms in the LG and both arms of the CG. Raw RF data were converted into images and measurements of skin thickness (ST), subcutaneous fat thickness (SFT), and muscle thickness (MT) were made using ImageJ software.

Results: Arm ST ($p < 0.0001$) and SFT ($p = 0.006$) were significantly greater in the affected when compared to the unaffected side while MT was not different between arms. MT was not different between the LG and CG. The CG had significantly greater HGS ($p < 0.001$) than the LG. The HGS/MT ratio of the LG was significantly lower ($p = 0.034$) than the CG.

Conclusions: In this study, MT is unaffected by the lymphedema condition. However, for a given MT, HGS is lower LG vs CG. This strength deficit may be related to functional skeletal muscle anatomical differences such as cross-sectional area and pennate angle in the LG.

Supported by the Dr. Louis G Johnson Foundation

Title: Secondary Leg Lymphedema following Coronary Artery Bypass Grafting in a Patient who had a previous history of ovarian cancer

Author: Ann DiMenna, PT (CDT), Markham Lymphatic Centre (www.markhamlymphaticcentre.com)

Context: At the present time, there are a limited number of studies on patients at risk for lymphedema who also undergo coronary artery bypass grafting (CABG) with femoral vein harvesting. A patient who had ovarian cancer three years earlier (in 2012) had no reported swelling and underwent CABG treatment in 2015. Post-surgery, the patient presented with swelling, repeated cellulitis infections, and delayed wound healing in the leg where the femoral vein was harvested.

Objective: To demonstrate that complex bandaging for lymphedema can reduce the length of time for complex wounds to heal following CABG surgery in a patient with previous history of ovarian cancer.

Design: A standard case history obtained from the patient revealed no outstanding risks or complications. During multiple phases of treatment, pictures were taken of the affected leg and leg wounds. In addition, a standard treatment plan of Combined Decongestive Therapy (CDT) was implemented, including: skin care, wound care, manual lymph drainage, exercise and bandaging. CDT treatments were completed three times a week for three months.

Setting: Private practice (Markham Lymphatic Centre, Markham, Ontario)

Results: Within one month, the three open wounds closed completely. The lymphedema was stabilized and the client has returned to prior level of function and activities of daily living (ADL) with compression stockings.

Conclusions: Patients planning to undergo CABG surgery should be aware of the risks and potential onset of lymphedema related swelling, especially for those patients at risk from prior cancer treatments. As well, these types of surgeries are associated with cellulitis and delayed wound healing. A key treatment strategy to address lymphedema in these patients is Combined Decongestive Therapy, which can aid in wound healing and lymphedema volume reduction.

Title: Feasibility and preliminary findings of a pilot RCT on early compression therapy and individualized exercise in women treated for gynecological cancer

Authors: S. M. Shallwani^{1,2}, A. Towers^{1,3}, A. Newman¹, S. Salvador⁴, Z. Zeng¹, D. Thomas⁵, L. Gilbert¹, W. Gotlieb⁴

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Introduction: Compression therapy and exercise have been shown to be effective in the management of lymphedema and their early use after cancer treatment may be beneficial in preventing or controlling the development of lymphedema. Currently, there is limited knowledge on effective strategies to reduce the risk of lymphedema, particularly in the gynecological cancer population. Moreover, given the scarcity of research in this area, understanding factors influencing the feasibility of randomized controlled trials may enhance the quality of future studies.

Study objectives: The objectives of this pilot randomized controlled trial were to evaluate the safety, feasibility and preliminary effectiveness of a tailored intervention of early compression therapy with individualized exercise for women treated for gynecological cancer at risk of developing lymphedema. Additionally, we wished to evaluate the feasibility of the study procedures.

Methods: Fifty-one women with newly diagnosed gynecological cancer were recruited pre-operatively from two hospital sites, the McGill University Health Centre Royal Victoria Hospital and the Jewish General Hospital, located in Montreal, Canada. Study participants were randomized to an intervention group receiving six months of compression therapy and individualized education on exercise or a control group receiving usual care. The following outcome measures were collected at five time points (pre-operatively, 4-6 weeks, 3 months, 6 months and 12 months post-operatively): lower limb circumferential measures (tape measure), volume (perometer), body composition (bioimpedance spectroscopy), presence and characteristics of edema (clinical examination) and quality of life (EORTC QLQ-C30 questionnaire). Safety and feasibility of the intervention were tracked using cellulitis incidence (clinical examination) and adherence to compression (patient diary). In addition, rates of recruitment, retention, and assessment completion were tracked over the course of the study.

Results: This trial is currently in progress and is scheduled to be completed in April 2019. Of 109 women approached over 30 months, 51 consented to participate in the study (47% recruitment). Reasons for exclusion include declined participation, unmet inclusion criteria and incomplete pre-operative study assessments. Baseline characteristics of the 51 women include a mean age of 59.1 years, with a diagnosis of endometrial (n=33), cervical (n=13) or vulvar (n=5) cancer. Preliminary results will be presented at the conference.

Conclusions: Recruitment to trials exploring intervention strategies in women with gynecological cancer at risk of developing lymphedema is challenging but feasible. This study will provide preliminary information regarding the effectiveness of early compression therapy and individualized exercise in this population.



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Abstract Session: Advocacy & International Work– Saturday, November 2, 10:45am – 12:00pm

Moderator: D. Keast

Title: Creating an Informed Advocacy Platform: An Assessment of Lymphedema Issues and Concerns in Ontario

Author: Debbie Ciotti-Bowman BScN, Board Member, Lymphedema Association of Ontario

Context: Lymphedema is a chronic, incurable disease affecting an estimated 1 million Canadians. Current treatments focus on managing regional swelling and inflammation to prevent infection and irreversible tissue damage. Despite its prevalence, lymphedema-related healthcare, including patient education regarding chronic disease management, is inconsistently funded by provincial healthcare ministries.

Objective: A poll was conducted to describe disease-related characteristics, demographics and healthcare issues affecting Ontarians living with lymphedema; questions were accessible to respondents through the Lymphedema Association of Ontario's newsletter, website, and Facebook page. Patient needs, barriers to care, and disease education were explored through perspectives of patients, caregivers, and certified lymphedema therapists.

Results: Results included N=238 responses with 82% of respondents experiencing lymphedema (<18yrs-86yrs), 4% were caregivers, and 14% were certified lymphedema therapists. Of those with lymphedema, 37.5% experienced primary lymphedema and 62.5%, secondary lymphedema. The most commonly indicated cause of secondary lymphedema was cancer-related treatments with 51% of participants reporting not being told about lymphedema as a side effect of cancer treatment. Of those experiencing lymphedema, 42.9% reported cellulitis episodes. Findings demonstrated 45.2% of patients were unable to access care for their lymphedema, with 25% of this group reporting not having access to care within their region. Further, 50% of this group could not finance their care at all. Overall, patient/caregiver-respondents indicated insufficient income and inadequate private insurance as a barrier to adequate care, especially those >65yrs.

A shortage of disease-educated healthcare providers at hospitals, community and primary care sites was identified by all groups as another barrier to timely diagnosis and critical intervention.

Conclusion: Findings suggest that Ontario's lymphedema patients experience several challenges with regards to healthcare access and utilization. Further research is required using rigorous quantitative and qualitative methods to understand patient and provider needs to help achieve province-wide accessibility to organized lymphedema patient education and clinical care.

Title: International Lymphedema Framework Outcome Measures Project, ILF-COM. Initial Report from Canada

Authors: David H. Keast MSc, MD, FCFP – Co-director, Canadian Lymphedema Framework
Anna Kennedy – Executive Director, Canadian Lymphedema Framework

Introduction: The International Lymphedema Framework established an international project to standardize outcome measures in the management of lymphedema. Measurement of outcome in chronic edema/lymphedema management is subject to great international variation particularly in the areas of evidence, standardization and benchmarks. Canada agreed to participate in this study.

Aims: The survey has two inter-related aims:

- To provide greater understanding of the national and international challenges of chronic edema/lymphoedema outcomes in different countries
- To provide greater clarity on the requirements for effective chronic edema/lymphoedema outcome measures that can be developed and validated for international adoption

Methods: An international anonymous opinion survey tool, Survey Monkey, was used. Ethics approval was not required. The project was explained to the provincial associations who agreed to send a Letter of Information to their membership. The letter contained a web link to the survey. The Lymphedema Association of Quebec translated the survey into French for French speaking people. The Canadian Lymphedema Framework also sent the Letter of Information to its database. The survey was open to both patients and healthcare providers. A single entry point divided respondents into patients, with 9 questions and healthcare providers with 14 questions. The survey was open for 2 months. The data was collected internationally with each country receiving their aggregate data.

Results: Internationally 8014 individual surveys were completed. 713 Canadians responded representing a remarkable 8.9% of the total number of responses.

Conclusions: Canadian patients and clinicians are to be congratulated for their commitment to best practices in the management of chronic edema/lymphedema

Title: Lymphedema Impact and Prevalence International (LIMPRINT) study: The Final Canadian Data

Authors: David H. Keast, MSc, MD. CCFP, FCFP,
Ashrafunissa Janmohammad, MBBS, MSc, MPH, CCRP

Introduction: Lymphedema is defined as edema present for more than 3 months, affecting any site of the body irrespective of underlying etiology or concurrent co-morbidities. This study, LIMPRINT to assess prevalence and characteristics of lymphedema, was conducted at Parkwood Institute Research, a part of St. Joseph Health Care. Lymphedema is the most responsible diagnostic code for 670 patients from June 2006 to July 2018 (24% of all code patients) in the Parkwood Institute Wound Care Clinic. In all, forty sites in 10 countries including Australia, Canada, Denmark, France, Ireland, Italy, Japan, Turkey and the UK participated in this study.

Aims: To determine the prevalence and functional impact of chronic edema in the adult population at a national and international level using modular epidemiological tools and to determine the impact of chronic edema on the lives of patients using Demographic and disability assessment, Health related quality of life, Details of swelling, Wound assessment, and Cancer assessment.

METHOS: In Canada Study was approved by Western Ethics and data were collected from 6/2016 to 12/2017 in Parkwood Institute Research, London ON

Results: Internationally 13,016 participants enrolled in Core Tool of which 1359 participants completed the Module Tools. Canadian data were available from Core Tool but both Canadian and International data were available for the Module Tools. Our site enrolled 68 patients in both the Core Tool and the Module Tools. Comparisons involved 9 Tables and 8 Figures showing significant differences between upper and lower extremity chronic edema. Upper extremity edema is primarily related to post breast cancer morbidity while lower extremity edema is far more complex in nature with multiple co-morbidities.

Conclusions: When previous Canadian data along with Canadian LIMPRINT data are compared with available international data, the results are consistent. The LIMPRINT data provide a rich database for further evaluation

Title: Humanitarian Mission in Tanzania-Raising awareness in Africa

Authors: Ibrahim, M., Msc, PT, MUHC Lymphedema Clinic and lectures in the Oncology Rehabilitation course offered through the School of Physical and Occupation Therapy at McGill University.

Context: Lymphedema is a pandemic affecting an estimated 250 million persons around the globe. Worldwide, the most common cause of secondary lymphedema is lymphatic filariasis, a parasitic infection transmitted by mosquito vector. As millions of persons are affected by filariasis and as cancer rates continue to increase worldwide, both of which contribute to lymphedema, more education needs to be in place on the assessment, prevention and treatment of lymphedema particularly in Africa, where little currently exists.

Objective: A humanitarian mission took place through Terre Sans Frontière a non-for-profit organization, in Tanzania, Africa October 2018. The purpose of the mission was to increase knowledge translation skills to physiotherapists, and medical professionals particularly in lymphedema education, assessment, prevention and management in patients with lymphedema affected by cancer or lymphatic filariasis.

Design: Preparation for the humanitarian mission took around one year prior to departure. Colleagues, friends, and patients contributed (through donations) towards the equipment and resources (i.e., lymphedema bandages, garments, and supplies), which were brought to Tanzania.

Setting: The mission took place between three hospitals including Kilimanjaro Hospital Christian Medical Center (KCMC), Kibosho Hospital and St. Joseph's hospital. Education and knowledge translation was provided on the lymphatic system anatomy, diagnosis, assessment, prevention, treatment and management for lymphedema patients secondary to cancer treatment or lymphatic filariasis. General oncology rehabilitation education was also provided.

Patients or other participants: The patients assessed were primarily palliative oncology patients, while participants of the workshops and lectures included: local physicians, nurses, physiotherapists, medical residence from Europe, and physiotherapy students at the KCMC School of Physiotherapy and director of the Physiotherapy school.

Results: Verbal feedback was attained from the local physicians, nurses, physiotherapists, medical residence from Europe, and physiotherapy students at the KCMC, who all expressed an interest in the information presented. Multilayer bandaging treatment was taught to local physiotherapists and physicians using supplies donated by patients from Canada. Furthermore, liaison was made by the company Mediven (upon return) to expand their services to distribute to Tanzania, a country that was not previously covered under their roster worldwide. Liaison was also made with the director of the KCMC School of Physiotherapy, who is now in direct contact with Mediven. Several physiotherapy students in Tanzania continue to communicate with the physiotherapist in Canada regarding cases they encounter, to review the bandage treatment technique and discuss management of lymphedema for their respective patients.

Conclusions: The humanitarian mission allowed for knowledge translation to health care professionals in Tanzania. However, further formal training is warranted in Tanzania and many countries worldwide on the prevention and management of lymphatic filariasis and cancer-related lymphedema.

Title: Introduction Of A Provincial Compression Garment Program - A Collaboration Between A Patient Association And The Government

Authors: Anne-Marie Joncas¹, Rachel Pritzker¹, Marie-Eve Letellier², Anna Towers²,

Affiliation: ¹Lymphedema Association of Quebec, ²McGill University Health Center Lymphedema clinic, Montreal

BACKGROUND: Considering: 1) high cost of purchasing the compression garments needed to treat lymphedema, 2) non-compliance or poor compliance of lymphedema patients with compression, 3) medical complications resulting from inadequate compression treatment of lymphedema and 4) implementation in 2014 of a pilot project allowing limited access to compression (project administered by the Régie de l'assurance maladie du Québec [RAMQ] and initiated by the Lymphedema Association of Québec [LAQ]); the LAQ has relaunched negotiations with the Government to obtain a compressive wardrobe that meets the real needs of lymphedema patients.

METHODS: The pilot project, initially implemented for 3 years, included an annual reimbursement of 50% to 70% of the cost of a single compression garment, a single set of multi-layer bandages and a single donning aid. The LAQ mobilized patients, therapists and physicians to make the Government, whose interlocutor was the Direction générale de cancérologie (DGC), understand the issues. A petition was launched by the LAQ and communications were sent to MPs and leaders of opposition parties in the National Assembly. A presentation of the data and issues was made by the LAQ to representatives of the DGC on May 10th, 2018.

RESULTS: After the RAMQ and DGC shared data on program use of the pilot project with the LAQ, the RAMQ implemented on August 22, 2018 an enhanced version of the *Bandage and Compression Garments Program for the treatment of lymphedema*, based on scientific evidence and best practices.

CONCLUSION: This experience highlighted the strength of patient associations and their partners in mobilizing for appropriate and equitable treatment of lymphedema, as well as the benefits of effective collaboration with government authorities (DGC, RAMQ). The data collected over the next few years by the RAMQ will indicate whether access to a universal program encourages more patients to comply more strictly with their treatment.



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Abstract Session: Advancing Lymphedema Care– Saturday, November 2, 1:45pm – 3:00pm

Moderator: N.Dolgoy

Title: Modified decongestive lymphatic therapy to meet hospital treatment’s reality

Authors: Marie-Eve Letellier, Linda Henry, Chantal Turgeon, Amina Chelloug, Sarkis Meterissian

Affiliation: Breast Clinic, Royal Victoria Hospital, McGill University Health Center, Montreal

Context: Breast cancer-related lymphedema (BCRL) affects approximately 20% of survivors. The conventional treatment for the intensive phase of BCRL is daily decongestive lymphatic therapy (DLT). However, this is not possible in the context of our institution in regards of our workload. Therefore, we must find solutions to adequately treat our BCRL patients.

Objective: To contrast the amount of arm volume reduction in women post BCRL using a modified DLT versus conventional DLT.

Design: Three comparison of approaches were proposed to our patients: 1) Twice weekly multi-layer bandaging (“conventional DLT”), versus a modified DLT of either 2) Once to twice a week 2-layer cohesive system, or 3) Once a week neoprene breathable garment; combined with self-management education.

Settings: Approximately 300 breast cancer patients are seen annually in our hospital-based clinic. BCRL represents 28% of our practice. Our setting allows us to see BCRL patients once, and on occasion twice, per week during the intensive phase of therapy. All patients seen receive education on upper extremity dysfunction risk reduction strategies and self-management.

Patients: 77 BCRL patients presenting with more than 10% arm volume difference were proposed the conventional or alternative DLT intensive treatment.

Results: Arm volume pre and post-treatment is statistically significant within groups (p-value <0.001). Percent of volume change is statistically significant: 1) Bandaging = 45.5%, 2) 2-layer = 35.1%, 3) Neoprene = 36.2%, p-value = 0.007. Statistical significance is found for the number of times seen and the length of therapy: the Neoprene group was seen less then the other two groups (mean 3.9 visits, versus 7.6 and 6.8, p-value = 0.005), however length of therapy is more than twice as long (mean 66.9 days, versus 32.7 and 29.2, p-value <0.001).

Conclusion: Due to our hospital time constraint, we are now using neoprene breathable garment combined with education and self-management strategies to treat our BCRL patients. We find that it is cost efficient and leads to higher patient compliance.

Title: The needs, the benefits and the challenges of starting a breast cancer preoperative program

Authors: Marie-Eve Letellier, Linda Henry, Chantal Turgeon, Amina Chelloug, Sarkis Meterissian

Affiliation: Breast Clinic, Royal Victoria Hospital, McGill University Health Center, Montreal

Abstract (project in progress)

Context: In 2012, a prospective surveillance model for women treated with breast cancer was introduced in the literature. Since then, there has been growing evidence on the importance of a preoperative program in breast cancer care. Our institution has been offering education and specialized services for upper extremity dysfunction for the last decade. However, we were missing an important aspect of therapy as women were not assessed prior to their surgery. As a result, a preoperative program was launched two years ago.

Objective: To describe the needs, the benefits and the challenges of starting a breast cancer preoperative program.

Design: Retrospective analysis of a cohort study. The period of observation is from May 2017 to September 2019.

Setting: This project is conducted in a hospital-based clinic and is supported by the Quebec Breast Cancer Foundation.

Patients: Patients are referred preoperatively to our service by surgeons and/or nurses. Any type of breast and axillary surgeries are seen.

Results: Since the program was launched, 126 women were seen preoperatively. With regards to need, the majority of women found it reassuring to have the information prior to their surgery. One of the most important benefits of such a program is early detection: 10 are in "surveillance mode" as their postoperative measurements slightly increased and/or their range of motion decreased, 5 are followed for axillary web syndrome, and 17 were referred for compression sleeves as they developed lymphedema. One of the biggest challenges was to set up an automatic referral system triggered by very busy nurses.

Conclusions: The preoperative program we have, definitely has its place in the continuum of breast cancer care of our patients. It allows rapid and effective intervention, which ultimately maximizes the person's quality of life. There is a definite need for such a preoperative program which requires health care professionals, clerical staff and patients to work together.

Title: Retrospective report of 100 referrals to a lymphedema clinic

Presenter: Catherine McCuaig

A pediatric dermatologist working at the Sainte-Justine University Hospital Center, a clinical professor at the University of Montreal, and co-chair of the CLF.

Introduction: It is important for caregivers to recognize pediatric lymphedema, and to investigate and treat it appropriately. It is considered a rare 'orphan' affliction with an incidence of 1/6000.

Aim:

We wish to share our experience with over one hundred referrals to our lymphedema clinic in the past 10 years and propose a plan for initial investigation and treatment that is applicable to all health professionals.

Method:

We reviewed the charts of the patients seen in our tertiary university hospital and entered data in an excel format.

Investigation:

A complete history and physical examination are essential. Other causes of peripheral edema must be excluded. Therefore, laboratory screening should include verification of thyroid, renal, and hepatic function. Filariasis must be excluded. If intestinal lymphedema is suspected, protein, albumin and immunoglobulin levels should be verified. Lymphoscintigraphy, and now near-infrared fluorescence lymphatic imaging give functional assessment. Other imaging may be required to evaluate whether other vascular malformations are present.

Results:

We had a female predominance of 65.7%. 63.6% were Caucasian, 8% African or Haitian. 20% had congenital onset, and 32% were under the age of 1 year.

We encountered mainly primary more than secondary lymphedema in children. 10% had edema secondary to other causes. Isolated primary lymphedema was seen in 63%. Lower limb involvement was seen in 73%, 19% upper limb, and 3% in genitals. Milroy's was in 7 and Meige in several others. More complex genetic syndromes such as Turners, Tuberous Sclerosis, Phelan McDermid, SOX 18, multisegmental lymphatic dysplasia. Lymphatic malformations accompanied lymphedema in several patients. Lymphedema is a harbinger of decompensating Graft vs Host disease.

Treatment and Conclusions:

Primary lymphedema in children is commonly due to genetic mutations, and is a hypoplastic lymphatic malformation. Treatment is multimodal, with decongestive therapy obtained through short stretch bandages, elastic stockings, and psychologic support to foster self-management.

Title: Comprehensive and Sustainable Cancer-related Lymphedema Education and Self-Management: Description of the model of care at Princess Margaret Cancer Centre

Pamela Hammond, RMT/CDT, MES, Aleksandra Chafanskaia, PT, MHSc, Stephanie Phan, OT, Reg (Ont.), HBSc (OT), Lydia Beck, OT, Reg (Ont.) MScOT, Eugene Chang, MD, and Jennifer Jones, PhD

The Princess Margaret Cancer Centre Lymphedema Clinic is part of The Cancer Rehabilitation and Survivorship Program (CRS). The CRS Program is an outpatient service that is supported by The Princess Margaret Foundation and provides compassionate and holistic impairment-driven cancer rehabilitation to patients at Princess Margaret (PM). The goal of the CRS program is to maximize quality of life, improve functional independence, and promote health and wellbeing.

The lymphedema care was first offered to PM patients within the breast cancer site in 2005 and was based on the principles of self-management and self-care. In 2012 a PM Lymphedema Clinic evaluated the clinic's 1:1 lymphatic self-massage (LSM) education and instruction and showed LSM training has enhanced breast cancer patients' LSM knowledge and skills.

Today, care is provided to patients from all disease sites and is delivered by a transdisciplinary team that includes physiatrists, physiotherapists, occupational therapists, and massage therapist trained in CDT. To meet the growing demand for lymphedema services and provide timely and patient-centered care, our program continues to focus on teaching patients' lymphedema self-management and self-care. After comprehensive assessment patients receive education and support, tailored training in self-management skills and strategies following 2006 International Lymphedema Framework guidelines. Patient education is delivered in group and 1:1 format. In cases where patients have issues such as unresolved pain, reduced mobility, axillary cording, a referral to the Toronto Rehabilitation Institute is provided for hands-on treatment. Lymphedema patients in our program also have access to the CRS Cancer Rehab and Exercise (CaRE) Program, (Lebed) Healthy-Steps classes, and specialty consultations for other cancer-related impairments. Patients are discharged within one year and referred to community therapists trained in Combined Decongestive Therapy (CDT).

Over the past 3 years, new patient referrals to the lymphedema clinic have increased by 22% from 337 in 2015 to 410 in 2018.

Title: Inequalities in access to a “free” lymphedema assessment and follow-up service for Quebec patients with cancer-related lymphedema: beyond the obvious

Authors: Anna Towers, Sophie Miro-Fortier
Lymphedema Program, McGill University Health Centre, Montreal, Quebec, Canada

Context: Lymphedema associations in Canada have been actively advocating for access to lymphedema care. It is obvious that if patients have to pay for care there will be inequalities of access. In a previous study, clinician researchers in our “free” tertiary-care service for Quebec patients with cancer-related lymphedema noted an inequity: Quebec oncologists tend to refer patients from higher socioeconomic groups, in spite of theoretically available access to all. In the previous study we compared the occupational status of patients referred to that of the general Quebec population. 57.3% of referrals were patients from occupational groups 1 and 2 (professional and managerial jobs) compared to 39.3% of the general Quebec population (Statistics Canada 2017). Only 42.7% belonged to occupational groups 3,4 and 5 (small employer, skilled, technical or routine jobs) compared to 60.7% of the Quebec population.

Objective: As a follow up to the above study, we wished to further explore the reasons for possible inequalities in access to care for patients with cancer-related lymphedema.

Setting: An academic lymphedema clinic at the McGill University Health Centre, Montreal.

Design: We conducted a scoping literature review on access to supportive care services in Canada. Searching MEDLINE, 77 out of 297 articles consulted were judged to be relevant to this enquiry.

Results: The researchers found no literature on socioeconomic status (SES) and access to Medicare-provided assessment and treatment services for cancer-related lymphedema. More generally, there is scant literature on SES and outpatient supportive cancer care services. For cancer treatment itself, we know that both lower SES and travel time to cancer treatment have been associated with reduced attendance and poorer patient outcomes.

Conclusions: Hypotheses will be raised, to be tested in future research, concerning the reasons that lower SES groups might have reduced access to lymphedema assessment and follow-up care, even within the health care system.