

2017 Conference highlights

National Lymphedema Conference, Montreal

Canada's first national bilingual lymphedema conference

By Shirin Shallwani

Co-hosted by the Canadian Lymphedema Framework and the Lymphedema Association of Quebec, the 2017 National Lymphedema Conference welcomed over 376 people at the Omni Hotel Mont-Royal in Montreal, Quebec (October 27-28, 2017). Truly representing the diversity of lymphedema, the conference participants included patients directly affected by lymphedema and their supporters, lymphedema therapists, garment fitters, health professionals and research scientists. Throughout the two-day conference, the venue rooms and hallways were bustling with participants energetic and engaged in learning and conversation. From the welcoming registration process, to the stimulating plenary and breakout sessions, to the interactive opportunities with the exhibitors and associations, the conference was well organized, was extremely informative and offered a unique and special experience for everyone.

Conference program

The overall theme of the conference was focused on chronic edema and lymphedema as "a growing problem in Canada". The agenda was jam-packed with professional education sessions, practical and informative workshops, research seminars and collaborative opportunities. Over and above the main conference program, additional opportunities included industry-sponsored practical workshops on compression techniques, a full-day course on lymphedema management for community nurses provided by **Dr. Anna Towers** and **Robert Harris**, a specialized half-day workshop on pediatric lymphedema given by



Dr. Isabelle Quéré and **Dr. Catherine McCuaig**, as well as a meeting for provincial lymphedema association leaders. The Saturday lunch options included a pediatric lymphedema networking event, patient perspective sessions and a roundtable discussion on hospital clinics.

Plenary sessions

The plenary sessions were delivered by national and international keynote speakers



Shirin Shallwani is a physiotherapist and certified lymphedema therapist specialized in cancer rehabilitation. She is currently pursuing her doctoral studies at the University of Ottawa School of Rehabilitation Sciences and is involved with clinical research at the McGill University Health Centre Lymphedema Program.



and revolved around clarifying terminology related to edema, understanding the prevalence of lymphedema, addressing obesity in this population and exploring novel treatment approaches. An expert panel at the end of the conference permitted interactive opportunities for questioning and discussion with international leading specialists in lymphedema.

Chronic edema and lymphedema:

In their engaging and thought-provoking session, **Prof. Christine Moffatt** and **Dr. David Keast** highlighted the need for clarity and consistency in the use of terminology related to edema. Lymphedema has been defined as an abnormal accumulation of protein-rich lymph fluid caused by lymphatic malformation or damage (International Lymphoedema Framework, 2006). Unfortunately, there remains a general lack of awareness related to the diagnosis and treatment of lymphedema as well as a misconception that lymphedema only occurs after cancer, or specifically breast cancer.

Furthermore, the changing demographics of the global population, such as ageing, increased comorbidities (e.g. chronic venous disorders), reduced mobility and higher levels of obesity, may be contributing to the rise worldwide in cases of chronic edema, including lymphedema. The term “chronic edema” has been used to describe edema present for at least three months that does not subside with elevation and is associated with at least one skin or subcutaneous change (National Lymphoedema Partnership, 2015). This umbrella term recognizes a wide range of different causes, mechanisms and risk factors resulting in long-term swelling, the majority of which likely have a component of lymphatic involvement. Thus, chronic edema and lymphedema are not exclusive terms and lymphedema is an important part of the wide spectrum of chronic edema. The speakers highlighted that “chronic edema” is not a diagnosis in itself but a public health term that may assist key stakeholders in adopting a common language and result in a better understanding of the extent and impact of this heterogeneous problem. Moreover, embracing the use of such an inclusive term may improve the timely and appropriate diagnosis of various conditions associated with chronic edema and lymphedema, as well as enhance equitable access to tailored treatment options, such as compression therapy, for different segments of the affected population.

Lymphedema prevalence in Canada:

Understanding the prevalence of lymphedema, that is the number of people living with lymphedema, can shed light on the magnitude of the problem.



In their eye-opening presentation, national lymphedema experts **Dr. Keast** and **Dr. Towers** spoke about the challenges with measuring these figures, such as the limited awareness about lymphedema within the medical community and the public, as well as the lack of standardized methods

for diagnosis and early detection. Focusing on the Canadian level, they presented estimated figures calculated on published rates of primary lymphedema, cancer-related lymphedema and other co-existing conditions, such as obesity and mobility disorders (Keast & Towers, 2017). According to their analysis, it is estimated there are currently at least one million people living with lymphedema in Canada. Of these, about 150,000 cases are likely due to cancer, while more than half are considered related to morbid obesity. Despite the limited research on Canadian cases of lymphedema, recent studies have consistently demonstrated the association between non-cancer-related lymphedema and cellulitis infection, a potentially serious complication requiring immediate medical care. These findings highlight the severity and impact of lymphedema on Canadians and their health care system and demonstrate an urgent need to improve the awareness and management



of lymphedema in Canada.

LIMPRINT study:

Another exciting development in the area of lymphedema research at the

international level is the LIMPRINT study. As explained by **Prof. Moffatt**, chair of the International Lymphoedema Framework, this initiative is based on an international partnership and the purpose of this project is to “develop and validate an international prevalence methodology”. The goals of this work are to facilitate the assessment of the prevalence and impact of lymphedema worldwide and to demonstrate that chronic edema and lymphedema are part of a major global issue. Components of this tool include a core section, a clinical assessment, and specific modules (e.g. to assess disability, quality of life, swelling, etc.). This collaborative project involves 40 sites located in 9 countries with data collected on more than 13,000 participants. Preliminary analyses on this dataset revealed that the majority of people with lymphedema were female (71%) and had secondary lymphedema (84%), 16% of the cases had wound issues in addition to

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lymphedema and 34% were also obese. Interestingly, worse quality of life was reported in males and in people with wounds, morbid obesity and history of cellulitis. Many cases of edema were actually non-cancer-related and were commonly discovered in people with co-existing conditions within different settings, including both hospital and community sites. These results further emphasize the need to acknowledge lymphedema as a wider problem beyond cancer and consider its burden on patients, health care systems and societies in general.

Obesity and lymphedema: A common link between obesity and lymphedema is becoming increasingly recognized and,

in light of the global rise in obesity rates, understanding and addressing obesity are important aspects of lymphedema management. As **Dr. Tobias Bertsch** explained, despite the popular belief that obesity is simply caused by poor diet and low physical activity, multiple factors may actually be related to obesity, including genetics, epigenetics as well as biological, socio-cultural and psychosocial factors. During his dynamic presentation, he expanded on the pathophysiological connection between obesity and lymphedema, where fat (adipose) tissue can influence lymphatic contractility and lymphedema can further induce changes in adipose tissue. Thus, a reciprocal relationship between the two conditions appears to exist. Furthermore, obesity has been identified as both a cause and a risk factor for the development of lymphedema.



With respect to weight loss strategies,

strict diets and exercise programs have been most commonly reported. However, weight loss diets have not been found to be very effective in the long-term, with research suggesting 95% of people regain their weight within 3 years. Moreover, while exercise has numerous health benefits, a tremendous amount of physical activity is required to burn adequate calories for actual weight loss. With extensive clinical experience as a specialized physician at the Foeldi clinic in Germany, Dr. Bertsch provided general direction on how to address obesity in the context of lymphedema care. The first step is a change of attitude towards patients suffering from obesity. Recognizing the multiple factors associated with obesity and removing the blame from the patient can help reduce the stigmatization that commonly occurs with obesity. Secondly, a shift towards appropriate therapeutic goals, such as weight maintenance or stabilization of weight gain instead of weight loss, is needed. A treatment focus on individual wellbeing and healthy lifestyle practices (including the consumption of non-processed foods, the avoidance of sugar and the incorporation of daily activity) may be helpful in supporting this population. Finally, in some cases, bariatric surgery may also be considered in collaboration with a



multidisciplinary team approach to enhance long-term outcomes. This session provided valuable information and strategies to manage obesity in lymphedema practice.

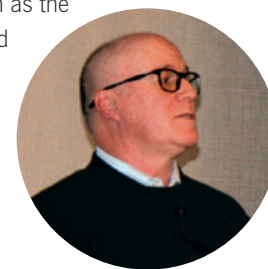
Surgical techniques: With the emergence of novel treatment approaches in the management of lymphedema, **Dr. Alex Munnoch**, a highly specialized consultant plastic surgeon from Scotland, spoke about the evolution of specific surgical techniques: lymphaticovenous anastomosis,

lymph node transfer or graft, lymph node transplantation, axillary scar release and liposuction. Based on his review of the literature and clinical experience, he reported positive outcomes in limb volume and quality of life after liposuction for a number of cases of lymphedema. However, Dr. Munnoch reminded us that this particular surgical procedure removes the bulk of the fatty tissue and does not treat the underlying condition of lymphatic damage or abnormality, typically resulting in the need for ongoing compression therapy. Moreover, the eligibility for such procedures depends on a range of considerations including the original cause of lymphedema, the availability of a specialized plastic surgeon and a multidisciplinary team (including a lymphedema therapist)

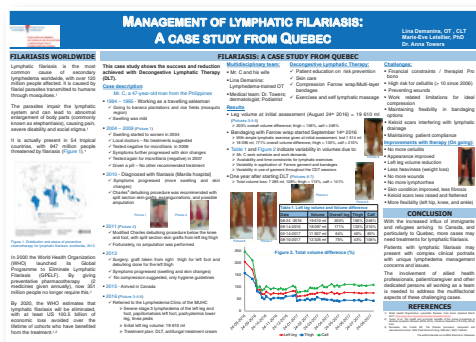
for long-term care, the adherence of the patient with previous decongestive therapy and ongoing compression as well as the risk of post-operative complications, such as infection and nerve damage. Nonetheless, as noted in this interesting session, the progress made in surgical procedures for lymphedema is exciting and such techniques may be beneficial for selected cases of lymphedema.

Concurrent sessions

A broad range of topics was covered within the concurrent sessions and targeted different groups of participants attending the conference. One important area of focus was the assessment of lymphedema and its impact through the use of patient-reported instruments, such as the recently developed Lymphedema Symptom Intensity and Distress Survey measures, as well as objective assessment techniques, such as ultrasonography. **Dr. Robert Kilgour** reported on physiological changes at the levels of the skin, subcutaneous fatty tissues and skeletal muscles in the presence of lymphedema. **Dr. Sheila Ridner** discussed the significant impact of lymphedema on



Congratulations to the winners of the poster presentations.



1st prize winner (and recipient of \$400.00): Lina Demanis, a CDT therapist from Montreal, Quebec. Her poster was entitled “Management of Lymphatic Filariasis: A case study from Quebec”.

2nd prize winning poster: “Decongestive Resistance Exercise with Advanced Compression for Breast Cancer Related Lymphedema Management (DREAM): A Protocol for a Randomized Controlled Trial”. M. Al Onazi and M. McNeely. The prize of a complimentary registration to the next lymphedema conference was awarded to Mona Al Onazi from Edmonton, Alberta.



Honourable mention poster: “Effects of Targeted Exercise Program on Time

Course of Upper Limb Function Post Radiotherapy in Young Adults with Breast Cancer: A Pilot Randomized Control Trial”. M. Ibrahim, T. Muanza, N. Smirnow, W. Sateren, B. Fournier, P. Kavan, M. Palumbo, R. Dalfen, M.A. Dalzell. The prize of \$150.00 was given to Marize Ibrahim, from Montreal, Quebec.

Peoples Choice award: “Is a 90-Minute Weekly Water-Based Exercise Enough to Control Swelling in Gynecological Cancer Survivors Living with Secondary Lymphedema?” An Indigo gift card was awarded to Azlak Tarig from Montreal, Quebec.

(Left to right): Lina Demanis, 1st prize winner of the poster competition, Anna Kennedy, conference co-host and Dr. Anna Towers, scientific committee co-chair.

patient wellbeing and functioning, as well as frequent concerns related to resources (e.g. insurance coverage) within this population.

Advances in treatment options, including innovative compression systems, skin care practices, psychological strategies as well as remedial and other exercise techniques (e.g. yoga and Tai chi), were also explored through various educational and practical forums. There was an emphasis on addressing the unique concerns of special populations, such as patients with pediatric lymphedema, lipedema and wound issues. [LP](#)



Conference abstracts and references can be found at www.canadalymph.ca.

Conference Summary

Key messages from conference sessions

- **“Chronic edema”** is not a diagnosis in itself but a public health term that may assist key stakeholders in adopting a common language and result in a better understanding of the extent and impact of this heterogeneous problem.
- It is estimated there are currently **one million people living with lymphedema in Canada**.
- **The LIMPRINT study** is a collaborative initiative to develop and validate an international prevalence methodology that may facilitate the assessment of the prevalence and impact of lymphedema worldwide.
- A reciprocal relationship between obesity and lymphedema has been recognized. **Addressing obesity in lymphedema management requires a shift in attitudes and therapeutic goals** and the consideration of multi-disciplinary and multi-modal approaches.
- **Surgical techniques**, such as liposuction, may be a promising treatment option for selected cases of lymphedema.
- Current work in lymphedema is **exploring patient-reported and objective assessment tools, innovative treatment approaches and special populations** (e.g. pediatric, lipedema and wounds).



Rachel Pritzker,
conference co-host.

The 2017 National Lymphedema Conference brought together people directly affected by lymphedema, health professionals, researchers, industry and policy makers to work towards the common objective of improving the care of people with or at risk of lymphedema. This event facilitated unique opportunities for learning, dialogue and networking and proved to be a productive forum enabling future progress in the field. Congratulations and much gratitude to the organizing and scientific committees, the Canadian Lymphedema Framework and the Lymphedema Association of Quebec, the sponsors, the exhibitors and the hardworking volunteers who dedicated endless energy, time and resources to ensure the success of this event!

2017 National Lymphedema Conference

The conference success would not have been possible without the generosity of our many supporters, who donate their money or time and who support our passion for furthering lymphedema education and awareness.



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Lymphedema Conference

Experiencing the future of lymphedema

By Anne-Marie Joncas

I've had arm lymphedema for two years now and have already attended two lymphedema conferences. Such events give attendees the equivalent of an advanced college education with an added human dimension. At the **National Lymphedema Conference (Montreal, Oct 27-28, 2017)**, participants nourished their minds as well as their souls with the art of managing lymphedema.

As a patient, participating in the conference gave me an ideal opportunity to see and touch the latest pressure garments and devices made by the major manufacturers.

I will certainly have plenty to talk about when I next see my compression garment fitter! One company took a photo of my hand with a digital imaging device that optimizes the accuracy of measurements to custom fit gauntlets. The effectiveness of this technology could ensure made-to-measure garments fit better from the outset.

Conference participants got a chance to enlighten themselves amidst truly inspiring people. I attended two important, patient-oriented lectures. The first was given by Montreal dermatologist, **Dr. Nicole Paquette**, and her nurse colleague, **Mélanie Poitras**. Together, they explained that skin care is crucial for lymphedema patients.

We were shown photos of cellulitis, a common infection for lymphedema patients, along with the full table of anti-biotherapy recommended by the International Lymphedema Framework. For Dr. Paquette,

whenever cellulitis is suspected, the approach is clear: due to the greater risk associated with lymphedema, it is best to treat it quickly with antibiotics even if this later proves unnecessary. Patients who had already experienced cellulitis asked clear and pertinent questions which revealed their anxiety about the serious complications that can ensue. They wanted to know the tell-tale signs that indicate consultation is necessary and where to go for prompt treatment, whom to consult for the right antibiotic, how one can be sure of getting the right medication and whether a patient who has already had cellulitis can keep a prescription on hand in the event of an emergency. Not only did these questions reveal the overall lack of resources, knowledge and direction that currently make it difficult for patients to avoid complications, they also emphasized the need for better support.

I found the lecture by **Dr. Marc Hamel**, oncology psychologist at the McGill University Health Centre, extremely valuable. He described how lymphedema patients are affected by many feelings: depression and non-acceptance, of unfairness and of being ignored by medicine and research communities, fear of being a burden to others, and of social isolation. Their coping mechanisms are overburdened by a chronic condition and they experience everyday difficulties in getting around, reduced mobility, sleep disorders, depreciated self-image, a disrupted sex life and the very real handicap that is lymphedema. Dr. Hamel demonstrated an in-depth knowledge of the range of emotions of anyone dealing with

lymphedema: sadness, anger, mourning, fear, shame, helplessness, despair, all challenges that accompany patients throughout their lives. To better deal with these adverse effects, Dr. Hamel suggested two helpful tools.

The first is mindfulness meditation, which enables us to come to terms with physical, psychological and relational changes while savouring the present moment. This approach encourages us to let go of ruminations, dark thoughts, regrets and apprehension about what the future may hold. The second is **Acceptance and Commitment Therapy (ACT)**, which begins with setting objectives that make sense to us and which give meaning to our lives. We first identify goals and people who are important to us and whom we hold dear, in order to take positive, constructive action despite our lymphedema.

I will certainly have plenty to talk about when I next see my compression garment fitter!

Slowly, this exercise should lead us to acceptance of our new reality as well as acceptance of others and their wide-ranging attitudes and reactions. We start by asking if we are ready to embrace a new way of seeing ourselves, the world and indeed, life itself. Dr. Hamel highlighted a range of psychological services which could be offered to anyone living with lymphedema.

In closing, I thank the courageous patients, inspiring volunteers, motivated therapists and caring doctors whom I met at the conference. You have my utmost admiration for your commitment and the example you set. You are the people who will determine the future of lymphedema! **LP**



Anne-Marie Joncas is a patient who chose to put her communication expertise at the service of the Lymphedema Association of Quebec. As a copywriter-translator for 30 years, she writes, among others things, for health organizations. She also does contract translation work for the Canadian Lymphedema Framework and the National Lymphedema Network (USA).