

LYMPHOEDEMA CARE AND MANAGEMENT IN CANADA

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Lymphoedema is a global health condition; one person in 30 worldwide is estimated to suffer from lymphoedema which has been termed 'the hidden epidemic' (MacDonald and Geyer, 2010). In developed countries, lymphoedema has been recognised as most frequently occurring after treatment for cancer (Cormier et al, 2010; McNeely et al, 2010). However, recent studies show that lymphoedema as a result of other causes is more prevalent than previously thought (Moffatt et al, 2003). Many patients in Canada suffer from lymphoedema but there are no data currently available to indicate this prevalence. Establishing the significance and impact of the condition will help increase recognition of lymphoedema as a healthcare problem, and is one of the priorities of the recently formed Canadian Lymphedema Framework (CLF). This article discusses the context and evolving state of lymphoedema management in Canada and the challenges and opportunities facing the CLF to improve care for patients.

Canadian context

Canada has a publicly funded healthcare system that functions as an 'interlocking set of 10 provincial and three territorial health insurance plans ... to provide universal access to medically necessary hospital and

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physician services' (Health Canada, 2011). Provincial and territorial ministries of health set policy and administer funds transferred from the federal government.

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As a result, lymphoedema care varies greatly across the country with access to care inequitable. Some provinces now provide coverage for certain aspects of lymphoedema treatment (primarily for compression garments); a few hospitals across the country offer complete decongestive therapy treatment (CDT) (usually restricted to cancer patients), while a larger number provide only lymphoedema assessment and patient education. Access to treatment, especially in rural areas, can be time-consuming and/or costly (Canadian Lymphoedema Framework, 2009). Timely diagnosis is also a problem as there are no specialists in lymphology in Canada, and very few physicians are trained in diagnosis and treatment of lymphoedema.

It is also known that lymphoedema has an impact on quality of life (QoL). A recent Canadian qualitative study of patients with lymphoedema and associated problems after breast cancer treatment, has highlighted the effects of disability on paid and unpaid work and the impact on family relationships (Thomas-MacLean et al, 2009).

Canadian Lymphedema Framework (CLF)

The CLF was launched in 2009 to improve management of the condition. Modelled on the International Lymphoedema Framework (ILF) based in the United Kingdom, the mission of the CLF is not only to improve lymphoedema management in Canada, but to contribute to global advancement as well. (CLF, 2010). The CLF is an incorporated non-profit organisation with charitable status led by a patient-physician collaboration. Provincial patient associations and representatives have been integral to the formation and continuing development of the CLF.

The first Canada-wide stakeholder meeting hosted by the CLF in November 2009 was attended by 108 patients, therapists, healthcare professionals, garment fitters, policy makers and industry representatives (many recruited through the patient associations). They met to discuss the challenges and opportunities to improve lymphoedema care in Canada (CLF, 2009). The key challenges identified were:

- ▶ Lack of awareness and knowledge of lymphoedema among healthcare professionals, patients and the public
- ▶ Insufficient education and standards
- ▶ Lack of access to treatment due to large geographical distances
- ▶ Insufficient numbers of trained therapists and cost
- ▶ Lack of evidence-based research supporting treatments
- ▶ Lack of a 'home' for lymphoedema and lymphology in the medical sciences.

To deal with these challenges and help implement their strategic plan, the CLF executive created an advisory

board and three working groups that are now active in the areas of education, research and partnership development.

Education

Among the CLF priorities, education has emerged as the broadest issue. It affects every aspect of lymphoedema care and management, from the individual patient and family members, through healthcare professionals, therapists and fitters, to policy makers and funders (CLF, 2009). Educational presentations about lymphoedema to medical and allied healthcare students do take place, but are sporadic and dependent on individual initiative, and are not integrated into the university curricula. Generally, lymphoedema and the lymphatic transport system have a minimal place in the university curriculum of most healthcare professionals across this country (CLF, 2010). Basic education about the lymphatic system and its disorders, and about lymphoedema risk and management, is needed in all medical and allied healthcare university curricula.

Lymphoedema therapists are trained in CDT through two private Canadian schools, or one of several private schools in the United States. As in other countries, there are no national government-recognised standards of training and no accreditation of lymphoedema courses in Canada. In the US, the Lymphology Association of North America (lanac@clt-lana.org) was founded to establish minimum competency standards and a national examination for therapists (lanac@clt-lana.org 2008). Provincial lymphoedema associations in Canada tend to refer patients to therapists trained in schools that provide the LANA minimum. However, not all therapists or healthcare practitioners providing lymphoedema care are trained to those standards.

As in Japan and other countries, admission qualifications to CDT courses are not yet determined, or do not require university-level health sciences (Matsui et al, 2008). CDT is a non-invasive procedure, therefore it is not under regulation by professional

governing bodies. Many lymphoedema therapists in Canada are massage therapists, some are physiotherapists, fewer are occupational therapists, nurses or doctors. Although massage therapy is regulated in three provinces (with limited healthcare coverage in only one province) and some massage therapists do work in hospitals, in general they are outside the government-sponsored healthcare system. With massage therapists and physiotherapists providing the majority of lymphoedema treatment outside the hospital system, lymphoedema care can be costly or inaccessible to many patients. Issues of accreditation of therapists and the accessibility and cost of treatment are not unique to Canada, and discussions on an international level may contribute to developing strategies and policies to meet these challenges.

The CLF promotes the use of the ILF Best Practice International Consensus document (International Lymphoedema Framework, 2006). In a pilot effort to broaden the knowledge base among nurses, physiotherapists and occupational therapists who work in Montreal hospitals, a series of workshops have been held to encourage implementation of best practice for lymphoedema management. Increasing the knowledge base among physicians is also an objective of the CLF, and articles have been submitted for publication in journals accessed by physicians. The education committee of the CLF is compiling a database of the level of lymphoedema and lymphatic education offered in medical and allied healthcare programmes, as a first step to understanding and improving education to healthcare professionals.

Highlights of recent Canadian research

The CLF is committed to seeing clinical practice in Canada based on solid research evidence and is aware of the need for large studies looking at components of the treatment presently delivered. A number of Canadian researchers have, however, published influential studies concerning the safety of exercise for lymphoedema patients (Harris and Niesen-Vertommen, 2000; McKenzie and Kalda, 2003; McNeely

et al, 2009). A pioneering study on the effect of upper body exercise and dragon boat training, has meant that participation in dragon boat paddling has become popular among women treated for breast cancer around the world (Lane et al, 2005; McCausland, 2010). Recently, a joint Australian-Canadian study of teams of breast cancer survivors attending a dragon boat competition reported that air travel did not cause significant change in the arms for the majority of participants (Kilbreath et al, 2010). While the impact of this research result cannot be generalised to the wider at-risk population, it is a positive indicator that the authors hope will prompt a larger study with a broader population.

While much of the larger picture is still unknown, and many physicians are still uneducated about lymphoedema, research is also underway in Canada in a number of different lymphoedema-related fields. A multidisciplinary team is investigating the incidence and impact of lymphoedema and related upper extremity disabilities on work, physical and psychosocial issues in women treated for breast cancer across Canada (Thomas-MacLean et al, 2008). Others are contributing to the palliative care literature (International Lymphoedema Framework and Canadian Lymphoedema Framework, 2010; Towers et al, 2010). A team has been investigating the effect of CDT on women with lymphoedema following breast cancer (Dayes et al, 2008). Another active group has recently undertaken a systematic review and meta-analysis of conservative treatments for lymphoedema, including not only CDT and its components but also dietary interventions (McNeely et al, 2010). In basic science, the team at Sunnybrook Research Institute has made important contributions to our understanding of lymphatic function and the pathophysiology associated with cancer-related post surgical lymphoedema (Tobbia et al, 2009).

3rd International Lymphoedema Conference

The CLF was successful in its bid to host the third International Lymphoedema Conference June 16–18, 2011 in Toronto. The conference is

under the auspices of the International Lymphoedema Framework (ILF), the CLF and the Lymphedema Association of Ontario (LAO). In addition to the three days of academic, scientific, and community-based presentations, there will be interactive workshops, and meetings of the ILF and the various national frameworks and representatives from around the world. A one-day session of special interest to patients, family members and caregivers is planned, as well as a day's introduction to lymphoedema and its management for healthcare professionals new to the field. In addition, an introductory educational workshop on lymphoedema and its management is being organised for physicians only.

The conference is seen as a unique opportunity, bringing leading lymphoedema researchers and experts from around the world to Canada. Such an event should contribute positively to improvement in attitude, education, knowledge and understanding of lymphoedema among healthcare professionals, physicians, nurses, physiotherapists, therapists and patients.

Summary

Patient associations are powerful advocates and have done much to raise public awareness and to get some coverage for treatment. The major challenge in Canada continues to be lack of awareness among physicians of lymphoedema as a diagnosable and treatable health condition. The most formidable task is to get the topic of lymphoedema included in the curricula of medical and allied health practitioners, and to increase the evidence base so that physicians can be convinced of the effectiveness of the components of lymphoedema treatment. The CLF is working with the ILF and other national frameworks on strategy and related action plans.

There are many challenges to improve lymphoedema management in Canada. However, both the challenges and solutions are similar world-wide. The opportunity to work together in building results is the mission of the ILF and its allied national frameworks.

In April 2010 the CLF undertook the first lymphoedema landscape assessment in Canada. This first step in collecting data on the current state of lymphoedema management in Canada will provide an important benchmark

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as the CLF moves forward to shape strategy and measure progress. The ILF partnership model of patients and academics, care givers and researchers, industry and educators has already borne fruit in other countries. Within this framework, the CLF is active in creating opportunities nationally to improve lymphoedema management and is committed to working with others to effect change world-wide. **JL**

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