# The rising prevalence of lymphedema in Canada:

# A continuing dialogue

## Accurately estimating lymphedema rates in Canada is not easy

By David Keast and Anna Towers

**How many people in Canada suffer with lymphedema, or with chronic edema with lymphatic damage? This question about prevalence rate is deemed important by lymphedema associations, by Ministries of Health, and by compression garment manufacturers and others. Although the lymphedema rate in Canada is increasing, it has been difficult to obtain accurate estimates of prevalence. In the following dialogue, Drs. Keast and Towers, two recognized Canadian lymphedema experts, seek to partially elucidate this issue with preliminary discussions.**

**Dr. Keast:** Chronic edema/lymphedema worldwide is poorly recognized and often poorly treated. It is often considered by clinicians either to result from cancer and its treatment or to be primary. This assumes that lymphedema arises only from absence or damage to the lymphatics. If one reviews the physiology of tissue fluid management in the body one realizes that lymphatic dysfunction will result from tissue fluid overload regardless of its origin. There is growing recognition that chronic inflammation ultimately leads to disordered lymphatic function and subsequent damage to the lymphatics. The current accepted definition of chronic edema/lymphedema is chronic edema lasting more than 3 months, minimally responsive to limb elevation and/or diuretics and with one or more secondary skin changes such as a positive Stemmer's sign. In a review of 326 patients treated in our clinic (Parkwood Institute Chronic Wound Management Clinic) we determined that our patients had an average of 7.3 co-morbid conditions. Those considered to be risk factors for lymphedema included chronic venous disease (75%), non-cancer related surgery (61%), morbid obesity (45%), trauma (20%) and paralysis (3%).

**Dr. David Keast, MSc MD FCFP** is a physician specializing in wound care and lymphedema and Clinical Adjunct Professor of Family Medicine, Schulich School of Medicine and Dentistry, Western University, London. He is the Co-Chair of the Canadian Lymphedema Framework.

**Dr. Anna Towers, MD FCFP** is Director of the Lymphedema Program at the McGill University Health Centre, Montreal. She was Co-Chair of the Canadian Lymphedema Framework from 2009-2015 and continues to be active in its various working groups.

**Dr. Towers:** Thank you for that review. What your review shows is that by far the most common risk factors for chronic edema/lymphedema are not cancer-related but rather *non-cancer* related. Estimating the prevalence for *non-cancer* related chronic edema is an important exercise. However, physicians do not diagnose these conditions as such, so we do not have Medicare diagnostic data to help us. Also, in the later stages of chronic edema many of these patients may show chronic inflammatory changes rather than pitting edema, with the result that clinicians may not use the terms chronic edema/lymphedema in their diagnosis. Bilateral legs are usually involved; there is no "normal" for comparison and to aid diagnosis. For all these reasons we can only come up with probable ranges rather than exact prevalence figures at this time. As for cancer-related lymphedema, it is relatively easy to estimate prevalence of lymphedema due to cancer treatment. We have national cancer statistics (even if they are a few years old) and we know the incidence of lymphedema after treatment for various types of cancer. We also have American estimates to guide us.

**Dr. Keast:** In 2009 the Canadian Cancer Society (www.cancer.ca) gave a figure of 810,000 Canadians living with cancer. Shaitelman et al in 2015[1] gave a prevalence of 15.5% of cancer patients with lymphedema. Survival rates are increasing. Conservatively we might estimate that the number of Canadians living with cancer is approaching 1,000,000. This would give a prevalence for lymphedema of

**1,000,000 x 0.155 = 155, 000**

which is consistent with the extrapolation from the American data.

**Dr. Towers:** However, this cancer-related lymphedema prevalence is greatly overshadowed by lymphedema and chronic edema caused by the rising obesity rate. International experts such as Christine Moffatt state that amongst those with a Body Mass Index of 40 and over (Obesity Class III), there is a 75-80% prevalence of edema with lymphatic insufficiency. Even if we say, conservatively, that there is a 50% prevalence of chronic edema in that population, we come to a figure of approximately 570,000 for Canada.

Prevalence estimates should be viewed as representing ranges rather than precise figures. However, we probably have 1 million or more Canadians impacted.

**Dr. Keast:** Yes, that estimate of obesity related lymphedema is based on Statistics Canada data (2007 - 2009) indicating that 3.1% of Canadians are morbidly obese (BMI>40). Given that obesity rates are increasing, the figure quoted may be an underestimate. Based on our own clinical data, 45% of our lymphedema patients were morbidly obese.

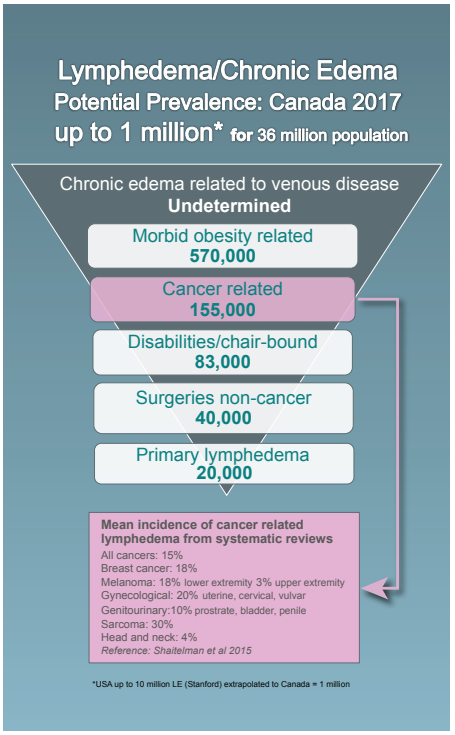
**Dr. Towers:** We then need to look at the prevalence in those with chronic venous insufficiency who are not also obese. Often the two conditions co-exist. How do we estimate those figures?

**Dr. Keast:** General estimates in developed countries put prevalence of venous leg ulcers at 1 – 2%. Prevalence of non-ulcerating venous disease is not clear with estimates ranging from 1 – 60%. Our patient characteristics show that there are multiple overlapping co-morbid conditions. In particular, there is significant overlap between obesity and venous disease. This means that counting venous disease patients separately risks double counting. We are still working to refine this estimate by going back to our data to see if we can separate out those with venous disease without obesity.

**Dr. Towers:** The other categories of persons with lymphedema that are unrecognized and untreated are those with disabilities and who are chair bound. This includes spinal injury, multiple sclerosis, stroke and cerebral palsy patients. According to the Canadian Survey of Disability (2012) there were almost 275,000 persons in Canada with mobility issues. Even if we conservatively estimate that only 30% of those have mechanical lymphatic insufficiency, we could add 83,000 to our total lymphedema prevalence figure.

**Dr. Keast:** When discussing immobility issues, we are referring primarily to lower extremity chronic edema related to dependency and failed calf muscle pump activity. Many assume that if the leg were elevated the edema would resolve. This has not been the case in patients seen in our rehabilitation outpatient clinics. Chronic edema ultimately leads to chronic low levels of inflammation and in turn permanent lymphatic dysfunction. Certainly, people who are chair bound are at higher risk, but fixed ankles and altered gait patterns lead to poor calf muscle pump activity. This in combination with other factors often leads to chronic edema/lymphedema.

Unfortunately, there are no published prevalence data for lymphedema associated with mobility related disorders. We can find data on the prevalence of these conditions in the Canadian population but we are forced to estimate the percentage that has chronic edema/lymphedema. For example, we know that there are 100,000




living with multiple sclerosis (Multiple Sclerosis Society), 86,000 with spinal cord injuries (Stats Canada), 14,000 with spina bifida (Wikipedia – 0.4/1000 live births in developed countries) and approximately 750,000 post-stroke patients (Public Heath Agency of Canada). In this case, we used a conservative estimate of 30% of those with mobility issues. More research is needed in this area. Our centre will be undertaking a prevalence study in our spina bifida patients.

**Dr. Towers:** We need to add the primary lymphedemas. The pediatric figure commonly quoted is 1:6000 live births. However, many manifest in adulthood. The international medical experts Weissleder and Shuchhardt (2008)[2] state that the figure is far more important than this, based on epidemiological studies from Germany. If we use the rate that these experts teach, we would put the figure at 20,000 for Canada and—again—this is probably an underestimate. Unless the primary lymphedema manifesting in adulthood is unilateral, it is very difficult to differentiate it from secondary lymphedema.

Then there are the surgeries other than for cancer. This includes a percentage of those with multiple abdominal surgeries, orthopedic procedures such as hip and knee

replacements, and surgeries involving vein harvesting, such as bypass surgeries. Add a conservative figure of 40,000 for that group.

**Dr. Keast:** Non-cancer related surgery was a co-morbid condition in 61% of our clinic's lymphedema patients. It was second only to venous disease. We did not include surgical procedures that would be unlikely to be related to lower extremity chronic edema/lymphedema. Hip and knee surgery as well as pelvic or abdominal surgery were included. Vascular procedures in the lower extremity were also included. Here again there is a risk of double counting. As previously mentioned our patients had an average of 7.3 co-morbid conditions. We are really seeing a population with complex lower extremity edema with multiple risk factors. Lymphedema in the upper body is counted in the primary and cancer related lymphedema.

**Dr. Towers:** There is a recently published paper by Moffatt, Keeley et al (December 2016)[3] where they attempted to estimate the point prevalence of lymphedema in Derby,

England. They examined people in hospitals, clinics, community nursing services and those attending general practices and report a point prevalence of 3.93 per 1000 population. However, they used a pitting test (and many cases are nonpitting), they did not assess the whole lower limb, and they examined a population that was institutionalized or using community services.

So, if you then use as your denominator the total population, which includes healthy persons, I think that you underestimate the problem. They do state that among the chronic edema patients that were in the community, 60% had experienced cellulitis within the previous 6 months. I think that this is important information about the morbidity related to chronic edema.

**Dr. Keast:** Population-based prevalence studies are always fraught with some danger. Was the population studied representative of the whole population or is the condition of interest over or under represented? In the Moffatt et al study, prevalence rose to 28.75 per 1000 for persons aged 85 or older. Thus, to extend the data to the overall Canadian population we would need to determine if the population demographics in Derby were statically similar to Canadian demographics. Nevertheless, the study does provide another piece in the puzzle of the prevalence of chronic edema/lymphedema. The data about episodes of cellulitis are important. Here again this data may be a little difficult

It is very important to note that these are preliminary discussions about prevalence, with actual figures to be elucidated with future studies.

to interpret, as it appears to be self-reported. Our experience is that cellulitis is over diagnosed in emergency departments. There are many conditions that may produce a hot swollen painful leg. Deep vein thrombosis is usually ruled out but a ruptured Baker's cyst may cause similar symptoms. The most common mimicking conditions are stasis dermatitis due to uncontrolled edema or acute lipodermatosclerosis. Cellulitis is such a burden on local emergency departments in our region that patients are seen the next day and followed in a separate cellulitis clinic.

**Dr. Towers:** So, putting the conservative figures together, we get to 870,000 chronic edema/lymphedema cases PLUS those with chronic edema related to venous problems who are not in any other category. Such prevalence estimates should be viewed as representing ranges rather than precise figures. However, we probably have 1 million or more Canadians impacted.

I think that the importance of this relates to finding health care resources for prevention and treatment. Within our health care system and our society we need to try to prevent the conditions that cause chronic edema/lymphedema in the first place. A large percentage of the adult population should be wearing professionally fitted leg medical compression garments for prevention. Certainly, this refers to anyone who is obese, who has chronic venous insufficiency, and anyone with reduced mobility from whatever cause. And, we need to advocate for programs that encourage exercise. Since it is proven that exercise is the best medicine for both prevention and treatment of almost every chronic illness, why are exercise programs, gyms and rehabilitation pools not more accessible, and subsidized by our health care system?

**Dr. Keast:** I agree. We know the risk factors for chronic edema/lymphedema. Patients need to be screened and those at risk need a coordinated program that focuses on helping persons at risk to self manage. The elements of such a program would include meticulous skin hygiene, appropriate exercise, compression therapy with funding for garments, and counselling and assistance with weight control. There is a need for research into post-operative compression therapy for procedures which have demonstrated a risk for lymphedema. Chronic edema/lymphedema is a complex problem in need of coordinated prevention and treatment. LP

A full set of references can be found online at **www.lymphedemapathways.ca**.