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Lymphedema Matters

A publication of the Lymphovenous Association of Ontario
Winter 2010 Volume 13 Issue 1

Lymphedema Wisdom

Our Lymphedema Conference panel of experts answer your questions



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Does lymphedema ever get cured or is it a condition that you live with forever?

AT: Chronic lymphedema is defined as edema due to lymphatic insufficiency that lasts more than six months. There are instances where lymphedema can be acute (for example, after surgery or an injury such as a sprain). However, chronic lymphedema is lifelong. It can be controlled so that it is minimal, with garments, exercise,

etc, but the tendency will always be there. Having said that, we are very interested in early preventive strategies in stage 0 or latent lymphedema that may prevent it from manifesting. This is an exciting area for future research.

Is it normal to feel pain with lymphedema?

AT: Lymphedema often co-exists with painful conditions such as neuropathy due to surgery or ra-

diotherapy. The lymphedema itself is said to be painless. Having said this, if a limb is very heavy it can lead to other conditions that can cause pain in the joints, muscles or soft tissues. Also, those with moderate to severe lymphedema may complain of discomfort such as tightness or a bursting feeling which technically speaking is a type of pain. Lipedema, a less common

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the lives of people
living with lymphedema*

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disorder of fat metabolism, is classically associated with pain and may be complicated by lymphedema in the later stages, which is often painful.

Would you recommend a lymphoscintigraphy test for anyone suspecting they have lymphedema?

AT: Lymphedema, especially that secondary to cancer treatment, is a clinical diagnosis in the vast majority of cases; a so-called diagnosis of exclusion. This means that lymphoscintigraphy is not necessary. The physician will rule out other causes of swelling and will do a reassessment of the cancer status. For primary lymphedema, or if the diagnosis is in doubt, then lymphoscintigraphy may be helpful. Interpretation of this test requires considerable experience and so it is not yet widely available in Canada. A facility may have the machine to perform the test but unless the radiologist sees many cases per month he or she will have difficulty interpreting the results.

Is any research currently being done in synthetic lymph vessels/nodes?

AC: To the best of my knowledge no current work is attempting to create synthetic elements of the lymphatic system to treat lymphedema. The two areas of greatest activity are gene transfer-type therapies and microsurgical lymph node transplantation. Dr. Stan Rockson at Stanford has written extensively on the former and would be an excellent source of information regarding any ongoing trials.

An increasing number of surgeons in North America are performing lymph node transplants. At present, no one has published long term follow up with high quality objective measures after these procedures. I believe that I represent the stance of many physicians treating lymphedema manually when I say that I am cau-

tiously optimistic and eagerly awaiting high quality data. Please bear in mind that surgeries can be harmful for patients with lymphedema and until we can accurately access the cost-to-benefit ratio of these procedures, we should proceed with caution.

Does low level light therapy (LLL) hold promise for lymphedema patients?

AC: Although the data remains preliminary, current evidence suggests that LLLT may improve lymphedema. Thus far studies have only been conducted on patients with breast cancer related lymphedema. Studies have examined LLLT both as a component of maintenance and acute, reductive lymphedema therapy. Treatment schedules vary, however the approach published by Pillar et al. seems to be most widely used: 3 treatments per week for 3 weeks, followed by a similar course of 9 total treatments after a 2 month break.

No significant toxicities or side effects have been reported with LLLT. If not beneficial, at least LLLT is unlikely to be harmful. That said, there has been long-standing concern in the laser therapy scientific community regarding stimulation of tumor cells with laser. Patients with known lymph node metastases should therefore avoid LLLT treatments to the axilla, groin, base of neck and/or abdomen depending on their cancer histories.

How does strength training benefit lymphedema?

AC: In a recent randomized, controlled trial, patients with breast cancer related lymphedema who performed full body strength training, including their affected arms, three times weekly for one year experienced several benefits - 50% fewer lymphedema flares, reduced lymphedema-related

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symptoms, and improved quality of life - related to a control group. All patients wore compression sleeves during strength training activities and did not alter their lymphedema management programs, e.g. wrapping at night. The strength training program began with low weight and few repetitions, and was closely monitored by specially trained staff. Participants' symptoms and their arm volumes were tracked for signs of worsening lymphedema. Once participants were successfully managing the low level strength training program, the amount of weight and the number of repetitions were gradually increased. With slow, progressive increases in resistance, many women advanced to the point of bench pressing over 80 pounds.

At this juncture we do not understand exactly how strength training may benefit patients with lymphedema. Strength training may create a better muscle pump in the lymphedematous arm that more effectively stimulates lymph vessel contractility and transport. However, such an explanation is speculative.

What types of research studies are being done in Canada concerning the quality of life for breast cancer survivors living with lymphedema?

RTM: I can only speak to my team's research, but to the best of my knowledge, it is the only one of its kind in Canada to focus on quality of life at this point in time. It is certainly unique in terms of its follow-up period (5 years) and the number of women enrolled (745). We will learn how many women will develop arm problems and what types of symptoms they have. More importantly, we will generate knowledge about the extent to which arm problems may be disabling and their impact on women's work, families and leisure activities. This research will help breast cancer survivors and their care

providers to better understand and treat arm problems and disability. Our research team members represent oncology, family medicine, psychology, physiotherapy and sociology. Our study has also had the support of 30 collaborators, with clinical/research experience in arm morbidity, and we have received funding from CIHR and SHRF, which has been essential to our work. For more information, please see: <http://qrc.usask.ca/rtm/arm.html>.

How can lymphedema impact one's social life?

RTM: That's an interesting question and an important one. Our research shows that women give up sports and hobbies which involve the arm, shoulder and/or hand. The wide variety of activities that are stopped or modified is astounding, which really demonstrates the impact of lymphedema. And, of course, there are social elements connected to many of these activities. Together with another researcher at the University of Saskatchewan (Dr. Liz Quinlan), I am exploring the healing potential of yoga for women with lymphedema. Although that study is in its early days, the women have reported that the social aspect of the yoga classes is very much appreciated.

Can long standing wounds cause lymphedema?

DK: Many wound care clinicians believe that chronic wounds eventually lead to localized lymphedema. Dr. John Macdonald calls it the "hidden epidemic". Chronic wounds set up a localized chronic inflammatory response which ultimately leads to damage to the peri-wound lymphatic system. Lymphatic drainage is reduced with the resultant accumulation of peri-wound lymph fluid which delays healing. Clinically this is observed particularly in lower extremity ulcers which heal much faster when the leg is placed in compression therapy even when

there is no obvious gross edema. People with chronic venous stasis disease, which is not managed with compression therapy, often progress to secondary lymphedema. The mechanism again is likely to damage the lymphatic system as a result of chronic inflammation and high output failure.

What is the key difference between the typical lymphedema in developing countries vs. what most people experience in Europe and North America?

DK: In developed countries, lymphedema develops primarily as the result of malignancy or its treatment, chronic venous stasis disease, chronic peripheral edema secondary to other medical causes or increasingly bilateral lower limb lymphedema secondary to morbid obesity. Primary lymphedema is a less common but just as devastating problem in developed countries. By contrast, particularly in sub-Saharan Africa and parts of Asia the main type of lymphedema seen is filariasis related lymphedema, caused by parasitic nematode worms which occupy the lymphatic system, including the lymph nodes, and in chronic cases these worms lead to the disease elephantiasis or stage 3 lymphedema. The parasites are primarily spread by mosquito bites. The lymphedema is caused by the inflammatory response to the infecting parasite. The initial stages are not painful and the disease often goes unrecognized until well advanced. While there are medications which can kill the parasites, the damage to the lymphatic system is permanent and must be symptomatically managed.

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RMT: University of Saskatchewan

CM: International Lymphedema

Framework—London, England
(held over for next newsletter).