Why doesn't my doctor know about lymphedema?

By Elliott Weiss

My lymphedema patients often complain that their family physician doesn't seem to know much about lymphedema, or even if they recognize the condition, offer little in the way of helpful management suggestions. Patients get frustrated and sometimes doctor-shop or seek out the advice of other healthcare practitioners. They look for solutions on the Internet or just give up in frustration.

Q How common is lymphedema?

A Worldwide, lymphedema is most commonly associated with filariasis. Lymphedema secondary to breast cancer is thought to affect up to 40% of women. Primary lymphedema can be seen in 1/10,000 people. Lymphedema can develop secondary to other malignancies, with chronic venous insufficiency, and/or following trauma. It is a misconception amongst physicians that lymphedema is a rare or unimportant condition. In fact it is very common but poorly recognized or acknowledged.

Q Why do physicians appear to know so little about lymphedema?

A Traditionally, physicians' knowledge of medical conditions focuses on diagnosis and treatment of diseases. In the case of lymphedema there are currently limited investigations available and treatment is generally non-pharmacological and non-surgical. So, for many physicians, lymphedema is viewed as a relatively untreatable condition with few medication or surgical solutions. Therefore little emphasis is given to physicians regarding the education, diagnosis or management of lymphedema. The passage of knowledge about lymphedema from physician to student is very limited in scope and depth.

Q How do we improve physicians' knowledge of lymphedema?

A There are different schools of thought regarding changing physician behavior. One view is that improving the education of medical students will have a positive impact on their knowledge and practice in later years. Other approaches include improving continuing medical education for physicians once they are in practice. Strategies include targeting physicians who are expected to see patients with lymphedema.

Q What about the role of research?

A The Canadian Institutes of Health Research (CIHR) promotes the "Knowledge-to-Action Cycle" as a guiding framework that outlines strategies to improve knowledge and physician behaviour. Lymphedema care in Canada could clearly benefit from this strategic approach, but implementation would require a Canada-wide academic commitment to improving care for all lymphedema patients.

Research activities could include bench-work, epidemiological studies and clinical trials while exploring new treatments within traditional complimentary or alternative models. The challenge is getting the attention of provincial and federal government organizations, health authorities, hospitals, and physician-based organizations.

Q What strategies could impact change?

A There is an urgent need to change physicians' knowledge and practice through a multi-dimensional approach. Each of the following recommendations on its own is insufficient to have a major impact:

1. Improve medical student exposure to lymphatic disorders and lymphedema management.
2. Develop lymphedema clinics in major medical centres with participation from vascular surgery, oncology, dermatology, physical medicine and rehabilitation, as well as primary care.
3. Lymphedema management should occur through a multi-disciplinary approach. Improving and standardizing the work of garment fitters needs to be addressed. The need for psychological support is critical.
4. Develop publicly funded health care resources to support research and clinical service delivery models.
5. Initiate a "Knowledge to Action Cycle" for lymphedema with the support of CIHR.

Over the past quarter century, there has been an awakening with regards to lymphedema care in Canada. With further energy and collaboration, we should all look forward to further improvements in the clinical management of this under recognized medical condition. LP

Elliott Weiss MD, FRCPC is a medical consultant in Physical Medicine and Rehabilitation in Vancouver, and Division Head, Physical Medicine and Rehabilitation, Providence Healthcare. He has been a medical advisor to the British Columbia Lymphedema Association since its inception.

Editor's Note:
The Canadian Lymphedema Framework will be offering a physician-only session at the National Lymphedema Conference in Calgary, October 23-24, 2015.

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