

Is the problem lymphoedema and its treatment or is it our knowledge?

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Why do we struggle gaining recognition from patients and healthcare systems about the importance of the early detection of signs of lymphatic system failure, when we have tools available to do this? Why do we struggle getting funds for lymphoedema screening programmes, when we have strong indications they work? Why do we struggle with a serious lack of knowledge in the healthcare professional population when it comes to lymphoedema? Why do we see apparently contradictory outcomes reported in the literature in trials, systemic reviews and meta-analyses? Why don't our healthcare systems seem to care? So many questions.

Maybe it's us. Maybe it's the words we use to describe lymphoedema as one form of chronic oedema. Maybe it's the lack of — or relatively tight — funding available to undertake reasonably large clinical trials. Maybe we don't collaborate closely enough, or maybe we just don't know what to do and neither do the patients.

Knowledge starts with education and, certainly, there is very little in medical courses focusing on lymphoedema. Vuong et al (2011) summarised findings from prior papers and discovered that about 50% of the Chairs in physiology departments at medical schools in the US indicated that 30 minutes or less are dedicated to lymphatics teaching with about 40% receiving 1–3 hours, while some only received 15 minutes. Incredibly, more than 60% thought this was sufficient! Furthermore, when lymphatic information was presented, it was only taught under the heading 'lymphatic information' 6% of the time. In the remaining 94% instances, it was presented in discussions relating to/as part of another of the bodily systems.

So we have much to do in terms of enhancing knowledge then. How can we

expect a GP or specialist to effectively deal with a patient presenting with lymphoedema with just this basic level of training? How can we ever expect them to gain an interest when they know so little about the lymphatic system and its disorders?

There is significantly more information presented in the area of chronic oedema. Maybe, since lymphoedema is a form of chronic oedema, we could think about changing the term we use? However, on the negative side, we would then lose 'lymphoedema' as being associated with damage, malformation or destruction of the lymphatic system. We would also perhaps lose the ability to develop the area of lymphatics and lymphoedemas into a speciality area in the future.

The origins of lymphoedema treatments (massage and compression) are many decades old and we are still discovering new things about the structure of the lymphatic system, with new imaging techniques, such as indocyanine green (Pan et al, 2008; 2013). Many treatments are undertaken based on information from trials that often were not conducted with as much control and rigour as they would be today. Trials often include a small sample size and can be heterogenous, leading, as could be expected, to differing or equivocal outcomes that when read by practitioners, patients and healthcare system insurers are unlikely to instil confidence in many treatment or management strategies.

Results from a recent trial, for example, showed no benefits from compression stockings for the prevention of lower-leg lymphoedema after inguinal lymph node dissection (Stuiver et al, 2013), but perhaps the *a priori* criteria of effects were too high. As another example, a meta-analysis by Huang et al (2013) indicted little or no effect of even one of the mainstays of treatment — manual lymphatic drainage — while a systematic review and meta-analysis on pneumatic compression pumps for breast cancer-related lymphoedema showed that while intermittent pneumatic compression could alleviate lymphoedema, there was no significant difference between routine

lymphoedema management with or without a pneumatic pump (Shao et al, 2014).

So why this variation in outcomes and uncertainty about treatment? Many review authors indicate it is related to methodology issues and rigour but, more often, related to the study group size. The confusion and uncertainty can be unsettling, but must be dealt with. We can only do better for our patients by working together, combining resources and, therefore, having a stronger voice.

I believe one step towards this can be made through our individual links to national and international groups, such as the International Lymphoedema Framework (ILF) and the International Society for Lymphology. At present, the ILF is working with its members and national frameworks to raise the profile of lymphoedema nationally and internationally, and to make lymphoedema a priority on national healthcare agendas.

The ILF also aims to help clinicians lobby for appropriate funding or reimbursement for lymphoedema care; address inequality of provision issues; implement and evaluate lymphoedema services based on best practice; and create an international lymphoedema community that collectively strives to improve the evidence base for treatment and professional practice.

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