Outcome measures for lymphoedema

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There are a range of significant issues that affect a person with lymphoedema which concern not only the patient, but also the clinician, healthcare professional, medical funds and the government. I acknowledge we must maintain a holistic view with these issues, such as the impact on quality of life (QOL), activities of daily living (ADL), time off work, productivity and social and psychological stigma.

However, our major focus and concern has always been an attempt to answer the question: How severe is the lymphoedema, how is it progressing, and what has been the effect of any treatment or management regimen on it?

To answer that question we have traditionally relied on circumferential measurements, linked to limb volume calculations on the basis of truncated cones. Sometimes these measurements are only of the affected limb, or in comparison with the contralateral limb. Rarely has the impact of limb dominance on this been acknowledged.

These measurements have been used as the major outcome gauge for short, medium and long-term studies. However, in middle and long-term studies, using such measurement can lead to errors, inaccuracy and misinterpretation. For example, a limb might increase in circumference (and volume) not because of a worsening of the lymphoedema, but due to an increase in body weight and/or perhaps an increase in muscularity as a consequence of increased limb use — thus, in reality, the patient has actually improved.

At a more subtle but practically important level, if we do not acknowledge lateralisation and handedness (i.e. a person’s strongest hand, often the one used to write with) (Bourgeois et al, 2010), not only are we ignoring the fact that these will influence overall limb composition (mainly in terms of muscularity), but also limb volume and the fact that there are significant underlying differences in asymmetry of the structure and functioning of the superficial lymphatic system in both normal tissues (Stanton et al, 1997) and those at risk of, or with lymphoedema (Stanton et al, 2001).

Rockson (2007) produced a summary of bioimpedance in the diagnosis and management of lymphoedemas and summarised the literature indicating that bioimpedance (when performed correctly) may ‘antedate the appearance of clinically identifiable disease’ and be able to help in the identification of ‘at risk’ individuals.

If we do not acknowledge and measure the variables Stanton et al (2001) know well, and if we only measure after the swelling is apparent, then we have some problems.

Can we talk about our clinical findings and outcomes with precision and certainty? Is there a gold standard?

In an earlier issue of JOL there was an interesting debate about this (Piller et al, 2009). It is clear that early detection and early recognition of lymphoedema have significant benefits, such as reducing excess medical costs and the incidence of cellulitis. However, the debate also revealed a paucity of evidence to indicate that early identification can really reduce the prevalence and severity of lymphoedemas.

Nevertheless, if there is one significant positive maybe we should act on it. So, why don’t we?

We also have another problem. On reading the plethora of papers regarding the incidence and prevalence of lymphoedema, and the effect (long and short) of treatment, we often seem to base many of these arguments on rather different foundations. The lack of a gold standard, when there could be one given our current knowledge and technologies, is a significant barrier to comparative interrogation of many trial outcomes.

Again, why is there a reticence to accept new technologies and use recommended standards?

We have excellent national and international consensus documentation to help us, but who has recently read them (European Wound Management Association [EWMA], 2005; Lymphoedema Framework, 2006a and b; Template for Practice, 2009; International Society of Lymphology [ISL], 2009), but who has recently used them? Admittedly they are often a little out of date when published, but they can be invaluable.

Maybe we feel most comfortable with what we learnt in our training programmes and pay little heed to...
what we read in the literature or gain from masterclasses, or from continuing professional development (CPD) courses. In the author’s opinion, changing seems to be a great problem for most of us. However, there must be a tipping point somewhere when an informed clinician or therapist says, ‘yes, there is enough evidence, I’m going to change’. But, are we there yet? I am convinced we are, but how do we enable it and act?

Ward (2009) in his paper asked the question, ‘Is bioimpedance spectroscopy ready for prime time as the gold standard measure?’, and discussed the serious issues we suffer through using inappropriate technologies (or making the incorrect interpretation from them), and strongly suggested that the evidence is out there for considering bioimpedance spectroscopy (BIS) as ‘the reference method’ for measuring lymphoedema.

For those using other current technologies, such as immersion plethysmography and perometry, it does not mean that their techniques are invalid. In fact, we already have much evidence to support strong correlations between BIS and perometry on a point comparison basis (Jain et al, 2010).

We had a paper in JOL about BIS (Ward, 2009) — but we had problems finding views of dissent. Why this imbalance in our enthusiasm and acknowledgment of the benefits of BIS and yet a seeming reticence to use it, or critically comment?

It is time that we all entered into a debate about this and similar issues relating to standards and consensus documentation. Why don’t more of us use the best technology available and recommendations made by expert groups. Too hard, too complex, too expensive, don’t know how to use them, or... Let’s hear your opinions. What are the pros and cons of a ‘gold standard’, why are many of us unwilling to change what we measure and how we measure to determine the status of lymphoedema, or of the effect of treatment on it? What is your reason, what are your views? Log on now to www.lymphormation.org and be heard. A summation of the views will be published in the next issue of JOL.

References


Template for Practice: Compression hosiery in upper body lymphoedema (2009) HealthComm UK Ltd, Aberdeen


A one-click site for keeping abreast of up-to-date lymphoedema-related resources, events and developments, both nationally and internationally.