Lymphoedema and the impact of social and societal factors – can we do better?

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Both secondary and primary lymphoedema continue to be a problem worldwide. Surprisingly, it's not only developing countries where remains an issue. But have we really performed much better over the past 20 years in managing this condition?

In developed countries, improvements have been made in the detection of cancers. Earlier detection means conservative interventions, less interference with the lymphatic vessels, and fewer nodes removed. 3D radiotherapy means a specific area can be targeted and surrounding tissues protected, not because they are shielded, but because the dose can be focused in three dimensions at a point even in the deep subfascial tissues.

Many surgical groups now combine cancer treatment surgery with reconstructive surgery – minimising tissue trauma and reducing the risk of unnecessary lymphatic damage and soft-tissue scarring, which is a major impediment to lymphatic vessel regrowth. Lymphatic imaging techniques have also improved with the introduction of indo-cyanine green to accurately show where the lymphatic collectors are and how they are working, so treatment can be better focussed on these patterns. We also have tools such as bioimpedance spectroscopy and tissue dielectric constants, which can detect small differences in tissue fluids in local and general areas (at a range of depths in the case of the latter). Unfortunately, for both of these treatment methods – despite what many believe is good science and strong evidence – these early detection techniques are used by only a few clinicians and therapists, and even then only in major centres. Surely is easier to manage fluids, rather than wait until there is the accumulation of fat in the superficial facial area and increasing induration of the fascia and above, and associated further lymphatic compromise?

For primary lymphoedema, we have the opportunity of genetic screening in developed nations, but costs are often beyond most of those at risk. This is unfortunate since we are more aware that many of the current secondary lymphoedemas may have an underlying genetic aberration. This leads to issues with the lymphatic system, ranging from an inability to pump hard, effectively, and with reasonable pressure, to less lymphatic capillaries and collectors, to disorganised collector paths and nodal hypoplasia.

Regardless of the country, it's often economic and social conditions that influence individual and group differences in health status.

We all have a range of risk factors in our lives, including our living and working environments. These coincide with individual factors (such as behavioural risk factors – like not taking care of our skin or not heeding advice about weight and diet management or genetics), which influence the risk of contracting a disease or disorder, or vulnerability to that disease or disorder. Broadly, these are classified as the social determinants of health.

There is strong evidence that these risk factors in the environment are influenced by public policies that reflect the influence of prevailing political ideologies and policies of those in governance. The World Health Organization (WHO) states: "This unequal distribution of health-damaging experiences is not in any sense a natural phenomenon, but is the result of a toxic combination of poor social policies, unfair economic arrangements (where the already well-off and healthy become even richer and the poor who are already more likely to be ill become even poorer), and bad politics."

The organisation goes on to state, "[...] these inequities in health, avoidable health inequalities, arise because of the circumstances in which people grow, live, work and age, and the systems put in place to deal with illness. The conditions in which people live and die are in turn shaped by political, social and economic forces".

In Australia, for instance, we have one of the better healthcare systems in the world, but for most people (with the exception of some in top-level private health) Medicare-paid access to adequate support for the basics of lymphoedema care – massage, garments, and bandaging – cannot be obtained; individuals pay for these themselves generally. Despite perceptions of best care up front, unless a patient has got the funds to support their own follow-up care, they won't get it.

The key principles for all of us to recognise and fight for are those linking to our social determinants of health; risk factors in our living or working conditions. At a basic level, these include access to adequate nutrition, education, safe water, healthcare; and wellbeing associated in policy areas covering housing, employment, transport, education, and the environment. For instance, in terms of the latter, living in a hot climate, compliance can be an issue. For example, it's not easy wearing a thick compression garment when its 35 degrees centigrade with 95% humidity.

Wherever in the world we are, there are strong social factors revolving around our level of employment, our financial status, and the level and type of health insurance. Just because one lives in a developed country does not necessarily mean better access to healthcare – even though the quality of healthcare may be orders of magnitude better than some developing countries. The society in which we live, our friends, family and colleagues also make a difference, our healthcare providers, our healthcare advice, and of course our compliance! Then we all have those practical issues: distance from healthcare providers, time taken to

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undertake treatment, time needed off work, and treatment fatigue to name but a few.

No matter where we live there can be poor health outcomes; not just those living in developing countries, but those at the lower end of the socioeconomic scale. Poor outcomes can occur for marginalised groups anywhere, and these can be linked to social exclusion, stress, limited education, and limited or no access to support.

So what do we need to do? We have good templates for practice, best practice statements and consensus documents, but these can be ineffective, if our social and societal factors don't allow access to their recommendations.

Groups like the International Lymphoedema Framework, the International Society for Lymphology, the European Society of Lymphology, and others need to work in concert with larger, politically strong groups, such as the WHO and the United Nations Development Programme, and the World Union of Wound Healing Societies, and think about how groups associated with wound care around the world have made significant improvements in patient outcomes for acute and chronic wounds, and how we might do the same for lymphoedema.

Maybe we need to realise that "lymphoedema", while a word describing lymphatic insufficiency, is not the right word to describe this chronic condition. Perhaps we have to link lymphoedema more with the term "chronic oedema". Very few die of lymphoedema, but those with the condition suffer immeasurably, with an enlarged limb, often deplorable quality of life, and sometimes with no one to turn to.

There are few other diseases/disorders in the developing and developed world that are so poorly acknowledged, managed, and supported by governments and health systems, despite (in the case of lymphoedema) a significant long-term loss of that person's productivity, as well as poor social acceptance.

We have an obligation to pool resources – both domestically and internationally – to: address the cost of lymphoedema care and support; improve access to, and funding of, garments; facilitate the education of clinicians and the public (particularly those at risk); and determine the best pathway to diagnosis, treatment and services.

It all starts with the pressure we can all put on governments and health systems to change political, social, and economic determinants of health, and thus of a chronic condition, such as lymphoedema.

Five per cent of women who undergo conservative sentinel lymph node removal and almost 20% who undergo axillary clearance develop lymphoedema in the USA (www.lymphnet.org). There is wide-ranging incidence of leg and genital lymphoedema (10%–60%) following groin clearances associated with bowel or reproductive system cancer treatment. It is also becoming clear that lymphoedema is more prevalent than the commonly quoted figure of 1.3 per 100 (indicated by the prevalence of the Stemmer sign; Pannier et al, 2007) and this is tied to the fact there are many more primary forms of lymphoedema than perhaps we would like to acknowledge (Brice and Connell, 2008). Add in the fact that many more are at risk of lymphoedema across the developing world and it begs the question – where is our voice?

References

Brice G, Connell F (2008) Lymphoedema: primary or secondary, how does one tell? *Journal of Lymphoedema* 3(2): 8–9

Pannier F, Hoffman B, Stang A et al (2007) Prevalence of Stemmer's sign in the general population. *Phlebologie* 36: 289–92