

# Our interest is swelling — but what's in a name?

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**W**e seem to have made strides in our ability to differentiate between lipoedemas and myxoedemas on the basis of clinical testing and presentation, but there is still a lot of uncertainty it seems when it comes to defining the boundaries between chronic oedema and lymphoedema.

We know that chronic oedemas are most commonly caused by elevated blood capillary pressures and we know the lymphatic system can fail to compensate for and remove the additional load. So when it does (or at least seems to) we use the

term 'lymphoedema', or for those more in the know, perhaps phlebo-lymphoedema. When the lymphatic system is malformed, damaged, or destroyed by cancer treatment, we call it lymphoedema.

We are also seeing an obesity epidemic in which one of the presentations is a limb swelling and associated fibrosis and papillomata, much like that of lymphoedema, but is it really lymphoedema?

There are differences between lymphoedema and chronic oedema, or so it seems. Many healthcare professionals may have problems defining and describing the differences in the late stages of them both without a barrage of test and history taking. But how important are these names? How important is it for us to continue to use different names for what might, in many respects, be quite similar? Is lymphoedema a poor neglected sister of the larger chronic oedema brother? Is there some benefit of changing the names? Is there some danger of losing the uniqueness of each? Whatever we decide, it's clear we all need to work together (Piller, 2009; 2016; Partsch, 2014), but how is this best done and under what conditions?

We have invited some experts from around the world to debate some of these points and look forward to hearing what our readers of the Journal of Lymphoedema think as well.

Neil Piller

## References

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**Lymphoedema or chronic oedema — what are we looking at, can we and should we distinguish between them, what should be or could be different in terms of treatments,**

**our expectation of outcomes, and what is essential and what optional?**

*JR* Outcomes will differ, especially when we consider the impact of obesity and also lipoedema. However, our staff should be autonomous practitioners who, on assessment, will differentiate and plan the most appropriate management. This does mean that we need to ensure that frontline specialists have the appropriate training and grade, and are the gatekeepers to all levels/types of service; this does not have to be medical as has been shown in several regional services. However, teams do need to have a wrap round access to specialist medical teams for consultation when required. This includes access to investigations and genetic testing.

Differences in care, I suppose, relate most obviously to surgical options. The basic principles apply to all, but perhaps the lipoedema/obesity options will be what we need to clarify to ensure efficient and effective care.

I think it is important to try and distinguish between different types of swelling, but not essential, and not at the expense of unnecessary medical tests. Key treatment is compression, regardless of what type of swelling (and obviously if there are no contraindications to compression). I agree that obesity-related swelling should focus on weight loss and healthy lifestyle. The role of medication in oedemas of mixed aetiology is important to consider, although this is not our area of expertise.

*BL* They are as different as apple and orange! Like congenital vascular malformation (CVM) versus arteriovenous malformation (AVM) and venous malformation (VM). Lymphoedema is ONE of many different conditions belonging to chronic oedema. They all do have different management strategies, as well as prognosis/long-term

outcomes (e.g. chronic venous stasis/insufficiency; drug side effects). Hence, proper differential diagnosis to sort out various natures, as we currently do, should be the starting point for the assessment. There should be no doubt before reaching the conclusion of lymphoedema. Not only local, but also regional and systemic causes ought to be included.

**VK** The term ‘chronic oedema’ was coined as an umbrella term to describe chronic swelling of all types of aetiology (Moffatt et al 2003) for the purposes of an epidemiological study. The word ‘chronic’ was defined as being present for at least 3 months. It was important to standardise a definition so that prevalence data from different geographical areas could be compared.

‘Chronic oedema’, therefore, encompasses lymphoedema, venous oedema, immobility-related oedema, oedema of advanced cancer and oedema of mixed aetiology among others. In most clinical situations, the cause of the oedema is not purely a lymphatic problem. In the clinic, it is important to consider the different components causing the oedema to enable appropriate treatment. For example, in older people with chronic swelling, heart failure may be a contributor to the aetiology. Treating the heart failure is, therefore, an important part of the management of such swelling.

Clinical outcomes are likely to be different depending upon the aetiology of the chronic oedema. For example, dependency oedema in immobile patients, who are unable to go to bed at night and therefore sleep in a chair, can be very difficult to control.

Furthermore, understanding the aetiology may help to define methods of preventing/reducing the risk of developing oedema. For example, passive exercises could be employed to try to prevent oedema associated with immobility, which is probably largely due to calf muscle pump failure.

**Which members of the healthcare team should be leads in the identification, differentiation, treatment strategies and processes? Can the lead be the same regardless of the origins of the swelling?**

**JR** Regarding care provision, I think we have examples of leads from across the multi-

disciplinary team and specialties. Currently, it all comes down to funding sources — and also interest to provide a service — sadly. I do, however, see many practices that are funded under the term ‘lymphoedema’ now accepting, or being referred patients, with all origins of swelling. Education of funders is, therefore, key.

I suppose the ideal model would be to have a medical doctor as lead for the more complex/unclear cases, although our model in Northern Ireland and Wales works well in that we have access to medical input when required. Having access to national clinics, such as St Georges and Derby, is important for the rarer conditions – but would not need to be the model for local commissioning. As already mentioned, many of the chronic oedemas progress and develop lymphatic issues, so it would be difficult to assign all oedemas to a particular category.

**BL** A family physician or general practitioner should initiate the investigation as a gatekeeper and set the right direction with the help by the referral specialists. Depending on the final diagnosis (e.g. iliac vein thrombosis), further management would be carried out by specialists (e.g. vascular surgeon to intercept the thrombosed iliac vein with angioplasty and stenting versus bypass).

**VK** The skill sets required to identify and differentiate types of chronic oedema depend on the aetiology concerned. For example, in breast cancer treatment-related lymphoedema the cause is usually clear (i.e. the effect of surgery and radiotherapy). Appropriate therapy can then be carried out. However, the healthcare professional also needs to be aware of the possibility of recurrence of breast cancer, which could worsen the lymphoedema and require anti-cancer treatment.

In other clinical situations, such as older people with multiple comorbidities, the aetiology may be more complex and a variety of factors may contribute to the cause of the swelling. It is helpful to understand these factors so that appropriate treatments can be initiated.

**RB** There will be regional variation in the members of the healthcare team, both from historical perspectives but also from healthcare practice and roles in the

local healthcare systems. Insight into professional strengths and limitations is required. Recognition of the need for a collaborative framework for the timely and efficient differential diagnosis leading to appropriate, evidence based and cost-effective management is essential. For example, the onset of unilateral lower limb oedema or lymphoedema can be assessed by appropriately trained clinicians, but differential diagnosis may or should require imaging to exclude other causes (eg May-Thurner syndrome) or more sinister causes (malignancy or vascular obstruction), or provide a conclusive diagnosis (lymphoscintigraphy). Collaboration in the clinical setting works well without the lead necessarily being a medical physician, provided that inter-disciplinary communication and collaboration exists. An appropriate qualified and experienced allied healthcare professional lead can and does reduce healthcare costs.

**Do we really need the two terms? What are the advantages and disadvantages?**

**JR** We are trying to get referrals into services as quickly as possible, so is lymphoedema always chronic? Can't we manage it in latency stage? On the other hand, chronic lymphoedema may lose the fluid aspect of its pathology to fibrosis and adipose tissue. Is lipoedema actually chronic oedema in an early stage? It isn't lymphoedema, at least insofar as it has got a functioning lymphatic system in the first instance.

**BL** Yes, we need two separate terms. We cannot lose the bird's eye view since many phleboedema with/without ulcer would proceed to combined condition of chronic venous insufficiency (CVI) and chronic lymphatic insufficiency (CLI) known as (secondary) phlebolymphoedema.

**VK** On the basis of the “new” understanding of the mechanisms of interstitial fluid production and removal, where reabsorption of fluid from the interstitial space into the venous end of the capillary is no longer felt to occur in the steady state, the lymphatic has the major role in fluid removal. It could be argued that all chronic oedema is lymphoedema, as failure of lymph flow to drain all the fluid filtered is a component of all oedema. In some situations, lymph flow is reduced

from normal (e.g. lymphoedema) whereas in others (e.g. venous oedema) lymph flow is increased as capillary filtration is high, but the increased flow is inadequate to keep up with the high filtration rate so that oedema develops (high output failure). In the latter example, over time, the lymphatic becomes damaged and lymph flow reduces.

Nevertheless, the term chronic oedema has advantages because of its general nature. Not only is it valuable in creating comparability of prevalence studies, but it encourages the consideration of the aetiology of chronic swelling in individual patients and therefore the appropriate treatment.

However, internationally, when the term 'lymphoedema' is used, many people consider this to be the swelling that occurs after cancer treatment and other causes of chronic swelling are not included. A lot has been done to change this concept and, therefore, a better understanding of the wider causes of lymphoedema (primary and secondary) is beginning to occur. The introduction of the term 'chronic oedema' therefore may cause confusion.

**RB** Yes we DO need the two terms as they assist in distinguishing patient groups in the clinical setting, which also provides a variety of clinical algorithms for appropriate management.

**What is your preferred general treatment/management strategy when a patient with a long-standing oedema presents?**

**JR** My preferred management strategy depends on the cause of swelling. A patient with previously untreated primary lymphoedema with typical lymphoedema skin changes will be treated differently to a person who has long-standing oedema due to obesity. Core management strategies for all patients should include self management, exercise and compression.

Self-management should be core to the treatment strategy. This must challenge the culture of "the therapist will fix me"! Partnership and accountability must be built into each management planning contract. This must have front-loaded education sessions as per all long-term condition models, such as the use of wrap round services, such as weight management classes and activity groups

in locality. Also consider the family picture — is it genetic?

**BL** Whenever there are predisposing factors for the condition to progress, despite maximum implication of conservative regimen (e.g. manual lymph drainage [MLD]-based, decongestive lymphoedema therapy [DLT] for lymphoedema), appropriate care should be considered to negate further progress or deterioration (e.g. lymphatic reconstruction including lymph nodes transplantation while in compensatory stage).

**VK** My preferred treatment strategy depends upon the cause of the oedema. However, at present, for most cases of chronic oedema, DLT is an appropriate part of the management.

**RB** Chronic oedema, which is differentiated from confirmed primary and secondary lymphoedema, is managed with education regarding causes and contributing factors to chronic oedema, skincare, appropriate elevation, sequential muscle pump exercises and compression therapy. If needed, a short course of compression bandaging to optimise prior to fitting compression garment can be beneficial. IF a wound is present, management of the wound with appropriate wound care and dressing is necessary. Low level laser therapy and compression may be helpful.

Primary and secondary lymphoedema management will depend on previous diagnosis and management, adherence and outcomes. Problem-solving with the individual is essential for people with long-standing lymphoedema to identify barriers to effective self-management and ongoing improvement.

**Where do we go in the future? What is the outlook for chronic oedemas given our obesity epidemic?**

**JR** Should we be lobbying for a return to good basic skin care across the board? This almost seems out of favor compared to other, more technical activities. Perhaps a world campaign to address hygiene and skin care (including footwear) would be a start! We need to front-load all patient intervention with a self-

management message (i.e. true shared care with associated responsibilities and accountability) including addressing healthy lifestyle management. Should there be classes to address this before any actual therapeutic activity takes place?

We need access to multidisciplinary bariatric services, including psychology, surgery options, dietetics and physiotherapy. We need support to treat the originating problem as without successful weight loss, we are not utilising resources efficiently. This is a core need across the world and all services are struggling.

We need access to regional follow-up (step down) clinics to take the pressure off the specialist teams and allow them to do what they are funded for. The follow-up teams (who can be a lower staff grade with senior leadership) can do the reviews and long-term garment prescription for the less-complex patient group. Currently many patients are discharged to the care of their GP in the UK, but with the huge number of garments available on prescription (despite best therapist recommendations) it is not necessarily what gets ordered. This would ensure a better use of GP time and also make prescribing a more effective and efficient practice. We should also be working with the key prescribing ICT companies to move compression garment prescribing to a level similar to that of controlled drugs (i.e. easily located and accurate). Currently, garments are not recognised as medical devices and there is no acknowledgement of the dangers of providing the wrong garment.

**BL** 'Exogenous' obesity is manageable, preferably in earlier stage before secondary lymphoedema becomes established (e.g. bariatric surgery). But the lipoedema is a different matter with different prognosis. In view of long-term morbidity, I personally prefer to consider this unique condition as a precondition of lymphoedema and take an aggressive approach with a pre-emptive strike with a necessary regimen for the lymphoedema (e.g. MLD, skin care and hygiene).

**VK** Understanding the aetiology of the different types of chronic oedema should lead to a better range of treatments. Obesity seems to be an important factor in the development of chronic oedema

and may be the sole cause in some people. Therefore, the prevalence of chronic oedema is likely to increase with the increase in obesity.

**RB** My clinical practice demographics have changed markedly over the last 2–3 years, suggesting an increase in awareness of both lymphoedema and chronic oedema. The difficulty is understanding why some obese people get oedema and significant early changes, while others do not.

#### What can we do to be more proactive?

**JR** We have to strive to educate the referring HCPs and push for early pick up and referral; this should be alongside active education of identifiable at-risk patient groups (not just leaflets, which we know patients rarely read). Pre-surgery education sessions to front-load the ‘health and wellbeing’ message might be an option for cancer-related lymphoedema; this is often now tagged onto the end of a cancer journey when the key learning and self-management time points have already passed. Up-front education would allow the patient to take control of their own body and direct care. Providing education would require a change in job description; all senior staff should have education as a key component of their role. Referrers must be continually stimulated to ensure timely and appropriate referrals. This is a cultural change for some clinicians, some managers, and ultimately some funders. We also need all services to be referring congenital and primary lymphoedema into local genetic testing centres with results shared with national data collections. Most cities have genetic centres but this is not always recognised as an easily achievable treatment adjunct. Additionally, we need to ensure outcome measures are inherent in all practices and that a minimum dataset is inherent in all practices.

**BL** We need to be more proactive in oedema and lymphoedema care; there needs to be a social campaign to warn of the risks involved to people with obesity, which is preventable if not reducible!

**VK** Weight loss in obese people seems to improve the oedema and is, therefore, a major component in the management of this problem. Conventional DLT is generally

felt to be less effective in obese people with chronic oedema unless weight loss occurs as well. Therefore, weight management programmes including bariatric surgery are an essential component to managing chronic oedema in obesity in the future.

**RB** I think we could all be more proactive with an early intervention, non-judgmental approach adopted with psychosocial support/surgical interventions for weight loss and limb reduction as appropriate in conjunction with conservative measures.

#### Is there some benefit of changing the names of oedema and lymphoedema, or there some danger of losing the uniqueness of each and their associated health funding and recognition?

**JR** As a manager who has worked long and hard for funding, it does seem to matter having different names as funders are beginning to know what lymphoedema is, but the term chronic oedema is still a bit too nebulous. Also many funders, such as Macmillan Cancer Care, will support clinics that focus on lymphoedema, but not on chronic oedema. It is a problem for the current thinking, and perhaps in the future this will change – but it has taken 20 years in the UK for the lymphoedema message to be heard!

**BL** I see no reason to consider changing the name since the recognition of ‘lymphoedema’ as one of the major players in chronic limb swelling has increased in the last decade. Indeed, as the fruitful outcome of active campaign mostly by phlebologists (not by lymphologists), the lymphatic system/circulation has been recognised as an ‘inseparable’ dual drainage system with venous system.

**VK** At present, the term ‘lymphoedema’ describes oedema due to failure of lymphatic drainage. This is usually used to describe a situation where the primary problem is failure of the lymphatic system. Other terms are sometimes used, such as phlebolymphoedema, to describe aetiology which is primarily due to failure of other systems, in this example the venous system. The failure of the venous system leads to subsequent failure of the lymphatics hence the term phlebolymphoedema. In this situation, it could be argued that

addressing the problem of the venous system failure may prevent subsequent failure of the lymphatics and worsening of the oedema. Therefore, by qualifying the term lymphoedema it is possible to draw attention to the underlying primary problem. So the term ‘lymphoedema’ could be used more widely with such qualifications. The term ‘chronic oedema’ more accurately covers the real world of oedema of mixed aetiology and, therefore, has some advantages.

Finally, it could be argued that the term ‘lymphoedema’ be used as a synonym for ‘chronic oedema’ to avoid introducing a new term but, at present, I think this could lead to further confusion.

**RB** A considerable amount of time and effort has been spent by many people the world over to increase awareness of both lymphoedema and chronic oedema — this appears to have gained momentum, with changes in referrals and increased awareness by healthcare professionals and public. Changing the names may create more confusion, but regional/national differences will impact on this in terms of funding. It is important to ensure that all appropriate healthcare providers are identified in the funding models.

#### Send us your comments

If you have anything to add to this debate, please email the editor, Adam Bushby, at: [abushby@omniamed.com](mailto:abushby@omniamed.com). All letters will then be passed on to the clinical editor, Neil Piller, and the best will be published in the next issue of the journal.