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She was too embarrassed to eat lunch with the other residents. I vowed to change all that.

JUNE – INDEPENDENT NURSE CONSULTANT

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

Neil Piller

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
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2014 CONFERENCE

Day Conference, University of Glasgow, 5-7th June
Online Conference, 29th May - 4th June

The full conference experience opens with a week-long online programme (29th May - 4th June) and follows with the main three-day event set in the beautiful historic buildings of the University of Glasgow, Scotland (5th - 7th June). The online conference is free to attend and both events are packed with presentations showcasing the latest research and ideas on lymphoedema.

2014 will be a notable year for Glasgow, Scotland – not only hosting sportsmen and women from around the world for the Commonwealth Games, but also having the honour and excitement of hosting the International Lymphoedema Framework (ILF) conference.

This conference will present exciting new developments in determining the prevalence of lymphoedema. It will focus on how the latest research offers the potential to reduce the incidence, prevalence and impact of lymphoedema on peoples’ lives. It will bring together international speakers from the fields of clinical practice, research and policy including Prof. Neil Piller from Australia, Prof. Christine Moffatt from the United Kingdom and Prof. Sugama from Japan. With over 100 presentations, seminars and workshops, the programme will be of interest to a wide range of delegates. There is special encouragement and support to those from developing economy countries, and for researchers new to the field of lymphoedema, to come and share their work, with awards being presented for best abstract and best poster. In addition, this year there are new awards for achievements in the course of your work and for those who inspire you; see the following website for details: www.ilfconference.org

One of the special tracks will be on eHealth – exploring how digital technology and social media can provide new opportunities in the field of lymphoedema. Presentations and workshops will examine approaches to improving care, sharing research and building learning communities, investigating new ways of delivering care, of learning and of working with patients for maximum impact. Another is dealing with complex lymphoedema. In addition, on 6th June, there will be an integrated Patients Day where some of the latest strategies for enabling self-management will be demonstrated and discussed.

Complementing the educational elements of the programme, there will be opportunities to build up your network of friends and colleagues. On the evening of 5th June, the Lord Provost will host a Civic Reception in the stunning Glasgow City Chambers (City Hall). On 6th June, a Conference Dinner will be held at the Thistle Hotel, Glasgow where you can experience the fun of an informal Ceilidh (Scottish music and dance), some mini Scottish Highland Games and the presentation of the awards.

What next?
The full programme will be available on the website when all the submitted abstracts have been reviewed and speakers confirmed. In the meantime, if you wish to submit an abstract for an oral or poster presentation or receive all the latest news of the conference programme and social events, please register your interest online at www.ilfconference.org.
We look forward to seeing you in Glasgow giving you a great Scottish welcome!

Margaret Sneddon, Chair of Organising Committee
Head and neck lymphoedema management practices

Amanda Purcell

Assessment, head and neck, lymphoedema, treatment

Abstract

Lymphoedema management of the head and neck is a valuable, yet under-recognised, area of practice. The author has embarked on a recent study trip to examine head and neck lymphoedema practices in the UK and USA, in comparison to those in Australia. Visits were conducted to established, hospital-based lymphoedema clinics in six major UK centres and two major US centres. A high degree of variability was observed in head and neck lymphoedema management practices. This article aims to document various assessment and treatment approaches for head and neck lymphoedema to improve awareness of the condition, to highlight the need for routine assessment, and outline the treatment modalities available.

Head and neck lymphoedema (HNL) can be classified as primary or secondary. Primary HNL is caused by congenital impairment of the lymphatic system and is rare. Secondary HNL commonly develops as a result of acquired damage to the lymphatic system during treatment for head and neck cancer or blockage by the cancer itself (Thoma, 2012).

Surgery and radiotherapy are the two primary modalities used to treat head and neck cancer and both can precipitate the development of HNL. HNL is most common following head and neck cancer surgery, but is most severe after treatment with combined surgery and radiotherapy (Micke et al, 2003; Lewin et al, 2010).

The prevalence of HNL is difficult to quantify, but in comparison to other types of lymphoedema, it is less common (Smith and Lewin, 2010). Reported HNL rates range from 12.1% (Chen et al, 2010) to 48% (Büntzel et al, 2007), to 75.3% (Deng et al, 2012) of samples of head and neck cancer patients. Such variation arises from the use of different definitions of lymphoedema, variations in the assessments used, and also due to the changing presentation of head and neck cancer.

Historically, head and neck cancer was mediated by prolonged exposure to alcohol and tobacco; presented at an older age (60–80); and, had a relatively low cure rate (National Cancer Institute, 2013). There is an increasing trend towards virally mediated head and neck cancer associated with the human papilloma virus (HPV; Chaturvedi et al, 2011). HPV-positive cancer commonly presents at a younger age (40–60 years) and is associated with relatively higher cure rates, compared with HPV-negative types (National Cancer Institute, 2013).

With the increase in HPV-positive head and neck cancer, patients may present with HNL at a younger age and survive longer than they would have done previously. Individuals who develop HNL may experience a greater impact from the morbidity of the condition and may be more active in seeking treatment.

Assessment

There is no gold standard test available to diagnose HNL (Deng et al, 2011), but a wide range of assessment tools are used to measure and monitor the condition. The complexities of the head and neck region make assessment challenging. Depending on the assessment used and the area examined, evaluation of lymphoedema can vary substantially.

Assessment of internal lymphoedema

Internal oedema cannot be physically palpated and is invisible without instrumentation (Deng et al, 2012), such as videofluoroscopy or endoscopy. Internal HNL can be described in terms of the degree of oedema present using the Patterson Scale (Patterson et al, 2007).

Internal HNL can affect swallowing with reports of up to 30% of people with HNL having associated swallowing dysfunction (Lewin et al, 2010). Internal HNL can occur in combination or in isolation from external HNL, as reported by Deng et al (2012) in a sample of head and neck cancer patients (n=81) where 39.4% had internal lymphoedema alone; 9.8% had...
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external lymphoedema alone; and 50.8% had combined internal and external lymphoedema. The use of informal swallowing assessment/screening can be employed to determine an association with HNL. Questions asked include:
- Is the swelling worse in the morning?
- Does it change throughout the day?
- Is your swallowing worse/better when your swelling is worse/better?

**Observations of current practice**

Internal lymphoedema assessment is not routine in most practices. Due to the additional equipment and expertise required, internal assessment is more common as a research tool.

**Assessment of external HNL**

External HNL describes visible swelling in the soft tissues of the head or neck (Deng et al, 2012). The most common locations for external HNL are the neck or submental region (Lewin et al, 2010; Deng et al, 2012). External HNL can be measured using objective or subjective assessments.

**Objective assessment**

The objective assessment of HNL has proved challenging for a number of reasons: the head and neck region is not a uniform shape; it surrounds many different anatomical structures; and it has no contralateral area for comparison. Assessments include:
- Palpation is used to feel pitting/thickening/fibrosis of the epidermis and dermis externally and in the intraoral compartment. This is an essential assessment in HNL (Thoma, 2012).
- Visual inspection is used to describe changes in the architecture of the skin and tissues; location of oedema; skin condition; oral mucosa and airways.
- Rating scales are used to systematise the descriptions obtained from palpation and visual inspection. Rating scales may combine qualitative and quantitative observations. Examples include: International Society of Lymphology rating scale (International Society of Lymphology, 2013; Table 1); MD Anderson HNL rating scale (Smith and Lewin, 2010; Table 2); Common toxicity criteria (Cheville et al, 2003; Table 3).

**Other more sophisticated assessments of HNL** have been reported in the literature, such as handheld scanning laser (Harrison et al, 2004), 3D optical scanning (Rana et al, 2011), ultrasound measurement (Piso et al, 2001). However, these methods were not observed in most clinical practices. This may reflect the additional challenges

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**Table 1. International Society of Lymphology (2013) rating scale.**

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Swelling is not yet evident despite impaired lymph transport. Subjective symptoms and subtle tissue/fluid changes may be present.</td>
</tr>
<tr>
<td>1</td>
<td>Early swelling reduces with limb elevation; pitting may be present.</td>
</tr>
<tr>
<td>2</td>
<td>Hard swelling that does not respond to elevation; pitting is present until late stages when excess fat and fibrosis may be present.</td>
</tr>
<tr>
<td>3</td>
<td>Lymphostatic elephantiasis; pitting may be absent; trophic skin changes present.</td>
</tr>
</tbody>
</table>

**Table 2. MD Anderson head and neck lymphoedema rating scale (Smith and Lewin, 2010).**

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>0</td>
<td>No visible oedema, but patient reports “heaviness”.</td>
</tr>
<tr>
<td>1a</td>
<td>Soft visible oedema; no pitting, reversible.</td>
</tr>
<tr>
<td>1b</td>
<td>Soft pitting oedema; reversible.</td>
</tr>
<tr>
<td>2</td>
<td>Firm pitting oedema (longer-lasting pitting); not reversible; no tissue changes.</td>
</tr>
<tr>
<td>3</td>
<td>Irreversible; tissue changes (not commonly seen in head and neck lymphoedema).</td>
</tr>
</tbody>
</table>

**Table 3. Common toxicity criteria v3.0 (Cheville et al, 2003).**

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Localised to dependent areas and no disability or functional impairment.</td>
</tr>
<tr>
<td>2</td>
<td>Localised facial or neck oedema with functional impairment.</td>
</tr>
<tr>
<td>3</td>
<td>Generalised facial or neck oedema with functional impairment (e.g., difficulty in turning neck or opening mouth compared to baseline).</td>
</tr>
<tr>
<td>4</td>
<td>Severe with ulceration or cerebral oedema; tracheotomy or feeding tube indicated.</td>
</tr>
</tbody>
</table>
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associated with these assessments, in terms of the expense involved in accessing the relevant equipment.

**Observations of current practice**

Palpation and visual inspection were the most consistently observed assessments followed by the use of HNL rating scales. Objective assessment commonly occurs at initial assessment and discharge; evaluation at other treatment points is less consistent. Clinics without a specific focus on HNL use more generalised assessments – such as observation – whereas clinics focusing on HNL use tape measurements or standardised photography.

**Subjective assessment**

Discrepancies between objective and subjective evaluation of HNL may occur. A bidirectional relationship is possible where a condition rated as moderate using objective measures may be subjectively perceived as either severe or mild. For example, Deng et al (2012) conducted a study with 30 participants, all of whom were objectively assessed as having HNL. When self rating their symptoms, only 13.3% of participants reported the presence of swelling in the head and only 16.7% reported the presence of swelling in the face. This discrepancy highlights the importance of recording both objective and subjective data. Subjective assessment of HNL and its associated symptoms can be made using the following tools:

- The Distress Thermometer (0–100; National Comprehensive Cancer Network, 2013) or Visual Analogue Scale (0–10; Torrance et al, 2001) can be adapted for use in measuring the level of distress caused by HNL.
- Symptom burden indexes record the presence of a range of symptoms common after head and neck cancer treatment (e.g. change in swallowing, talking, taste, and the presence of swelling). High levels of symptom burden have been reported in HNL patients in terms of frequency, severity, and distress (Deng et al, 2012). Symptom indexes are designed to record the number and/or intensity of symptoms present and can be used to monitor progress. Examples include: the MD Anderson Symptom Inventory (Rosenthal et al, 2007; 2008); the Lymphedema Symptom Intensity and Distress Survey – Head and Neck (Deng et al, 2012).
- Quality of life assessments have been developed for use following head and neck cancer treatment, rather than specifically for HNL. They commonly include measurement of communication, speech, appearance, swallowing, eating, and oral symptoms. No quality of life scales currently available contain specific reference to lymphoedema, however, related scales include: Quality of Life Instrument for Head and Neck Cancer (Morton and Witterick, 1995); Functional Assessment of Cancer Therapy (Cella et al, 1993); University of Michigan Head and Neck Quality of Life Questionnaire (Terrell et al, 1997); Head and Neck Cancer Inventory (Funk et al, 2003); the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Head and Neck 35 (Bjordal et al, 1994); University of Washington Quality of Life Revised (Rogers et al, 2002).

**Observations of current practice**

Subjective assessment was less common than objective assessment in the clinical practices observed. The Distress Thermometer and Visual Analogue Scale were the only tools observed in clinical use. Quality of life tools were not used clinically and may be more relevant as research tools.

**Treatment**

HNL is a complex condition with a variable presentation and thus a multimodal treatment approach may be required to achieve successful outcomes. The use of a wide variety of treatment modalities was observed in the clinics visited. Intensity and duration of modality application was also highly variable with some advocating only therapist-directed treatment and others recommending primarily patient- or carer-delivered treatment.

**Treatment modalities**

Manual lymphatic drainage (MLD) and light compression are reported as being the core HNL treatment modalities (Mihara et al, 2011; International Lymphoedema Framework, 2012). However, a wide variety of techniques are employed in practice:

- Compression of the head and neck is reportedly difficult to achieve (Mihara, et al, 2011) and should only be applied with low pressure (International Lymphoedema Framework, 2012) to avoid constriction and potential increase in facial oedema (Smith and Lewin, 2010). Compression bandaging with short stretch bandages can be applied under the chin and around the head, secured with a Velcro® attachment (Klose and Straßbenreuther, 2006) or cohesive bandages can be used to avoid the need for fixation (Gilbert et al, 2011). Bandages are generally low in cost, use materials available to most lymphoedema clinics, are relatively easily assembled, and can be adjustable to respond to changes in oedema. However, they can be cumbersome to apply and do not provide coverage of all areas of the head and neck. Compression garments are an alternative to compression bandages. Custom face masks are required to cover extensive areas of swelling – to support irregular anatomy – or for use with extensive oedema (particularly anterior cheek swelling). Off-the-shelf compression can be better suited to oedema confined to the neck region. A variety of inserts can be used underneath or within bandaging and garments: open cell foam in a flat sheet can be used to create bulk and increase the stiffness of the compression on tissues; closed cell foam in small pieces between tape can be used to “break up” areas of thickening.

- Exercise/movement aims to increase the individual’s range of motion and reduce the effects of fibrosis through the use of a range of motion exercises for the face, neck and shoulders, and composite range of motion exercises (e.g. neck extension and lateral flexion; Forster, 2006; Stubblefield, 2011). Exercise/movement can compensate for a reduction in natural muscle movements occurring as a result of eating softer foods, altered speech patterns, and reduced activity. If natural movement has not returned, prescribed exercises may assist lymph drainage, particularly if performed in conjunction with compression.
- MLD has been reported as the primary treatment modality for HNL...
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management (Lee et al, 2013) with positive clinical benefits reported (Piso et al, 2001; Smith and Lewin, 2010), however, strong evidence is lacking. Contraindications for head and neck MLD may include hyperthyroidism, hypersensitive carotid sinus, cardiac arrhythmia, and arteriosclerosis in the carotid artery (Strößbenreuther, 2012). MLD pathways follow the expected anatomical pathway of the lymph vessels (Thoma, 2012). However, recent anatomical findings have shown that the superficial lymphatic drainage of the head and neck is “virtually unpredictable” (Pan et al, 2008). Different lymphatic network patterns have been observed between subjects and even between different facial sides of the same subject (Pan et al, 2008) with vessels from one area of tissue draining to different lymph node groups (Pan et al, 2011) crossing the midline and crossing scars (Maus et al, 2012). These findings may indicate a need for more individualised MLD pathways in future.

- The implementation of a skin care regimen is recommended to maintain skin integrity and prevent infection (Lee et al, 2013). Cellulitis is a known complication of lymphoedema and, while rates in the head and neck region appear lower than in the limbs, limited data are available. In one of the few HNL treatment studies published (n=18), Piso et al (2001) reported a 17% infection rate.

- Elastic taping (e.g. Kinesio® tape) can be used to assist removal of oedema from congested areas by opening initial lymphatics and lifting superficial skin to decrease pressure (Kase and Stockheimer, 2006). In the absence of coronary artery disease or bruits in the carotid arteries, taping of the neck can be employed (Kase and Stockheimer, 2006; Coopee, 2011). However, if symptoms are present, taping in the neck should be avoided (Coopee, 2011).

- Scar/fibrosis management: techniques such as elastomer putty used under compression (Klose and Strößbenreuther, 2006), or myofascial release, are used to reduce scarring and fibrosis of the neck, and improve associated movement, as well as lymphatic drainage.

- Gentle inclination of the head and upper body when sleeping can assist drainage. The neck is held in a neutral position with caution to avoid excessive neck flexion. This position can be achieved by using a foam wedge, elevation of the head of the bed or the use of pillows.

- Deep breathing is used for the management of other types of lymphoedema and is inconsistently employed with HNL. Further research into the mechanism of action is required to facilitate evaluation of this technique.

Other treatments have been reported in the literature, but were not observed in clinical practice at the sites visited (i.e. cooling therapy [Rana et al, 2011], low-level light therapy [Lee et al, 2013], and surgery with lymphaticovenous anastomosis [Mihara et al, 2011]).

**Observations of current practice**

Multiple treatment modalities are available for HNL; however, each therapist demonstrated a preferential use of only one or two key modalities. The key modalities chosen varied between clinics however MLD and compression (with inserts) were the most commonly utilised. While the effectiveness of each technique appeared to differ between patients, the most consistently positive results observed by the author occurred with the use of gentle compression and inserts.

**Treatment intensity**

Perhaps the greatest variation in practice occurred in the design of HNL treatment programme intensity. The models observed fell into three broad categories. These were:

- Therapist-directed treatment followed by self care: using a therapist-directed approach (Piso et al, 2001), the therapist delivers treatments directly to the patient, requiring multiple clinic visits with the patient performing self management on the intervening days. This approach is commonly preferred for moderate–severe HNL due to the improved outcomes observed.

- Self care only (Smith and Lewin, 2010; Jeffs et al, 2011) is used for patients with mild to moderate lymphoedema to balance clinical outcomes with health insurance limitations, staffing restrictions, and patient travel distances. Training, provision of pictorial guides and instructions, and follow-up therapist review are all required to support this approach (Rockson and Vaillant-Newman, 2011). Advantages include reduced therapy resource use and patient convenience, however, self-management techniques may not be as effective as therapist-directed treatment (Rockson and Vaillant-Newman, 2011).

- An alternative approach is to commence a self management programme for a quarantined period, followed by therapist-directed treatment if self management outcomes have been unsatisfactory.

**Discussion**

The author observed the delivery of a wide range of treatments for HNL. There are several possible explanations for this variability. Different stages of HNL may be best suited to different treatments. Deng et al (2012) found that of those with HNL, some "had pure lymphoedema, some had a mixture of lymphoedema and fibrosis, and others had only fibrosis". Due to the frequent occurrence of fibrotic tissue following treatment for head and neck cancer, a combination of fibrotic tissue reduction techniques and lymphoedema techniques are required for clinical effectiveness (Klose and Strößbenreuther, 2006).

Further variability in treatment modalities may be reflective of the clinicians’ professional background and prior experience. HNL treatment is primarily provided by nurses, occupational therapists, physiotherapists, and speech pathologists. Each profession has its own inherent skill set that may predispose a clinician to a preference for certain types of treatment. For example, physiotherapists were observed commonly performing myofacial release, whereas speech pathologists focused on the interaction between lymphoedema and swallowing.

Perhaps the most likely explanation for treatment variation is the limited research currently available into HNL treatment. There is little evidence to guide clinicians in choosing the most effective treatment
References


Detecting subclinical secondary lymphoedema using bioimpedance: A preliminary study

Maho Takeuchi, Toyoko Yoshizawa, Yoko Kusaka, Yoshihito Furusawa, Yasuka Nakamura, Fumi Atogami, Hitoshi Niikura

Key words
Bioimpedance analysis, early assessment, secondary lymphoedema

Abstract

Background: Early intervention is an important facet of the prevention of secondary lymphoedema. However, it is difficult to predict symptoms before swelling becomes clinically significant. Aims: To detect the potential occurrence of secondary lymphoedema due to lymph node dissection (LND) by examining variance in body water composition from pre- to early post-operative phases. Methods: This prospective observational study was carried out on two groups of patients who had undergone gynaecologic surgery, with or without LND (LND and control [CONT] groups, respectively). Weight, lower-limb circumference, and the ratio of extracellular fluid to total body fluid (E/T) were measured preoperatively and on postoperative day 7 (POD 7). Results: Eighteen patients completed the study (LND group, 12; CONT group, 6). Two patients in the LND group had genital swelling on POD 7. In the LND group, a significant increase in E/T in the right leg and body trunk was observed. Conclusion: Early changes in LND group E/T were observed. Further studies are required to develop a reliable index for predicting the occurrence of lymphoedema.

Secondary lymphoedema reduces both a patient’s physical and psychological quality of life (QOL; Franks et al, 2006; Chase and Wenzel, 2011; Fu et al, 2013) and is frequently seen in cancer patients after treatment that includes lymph node dissection (LND) or radiation therapy (Moffatt et al, 2003). The major symptoms of lymphoedema include discomfort, heaviness, problems with physical mobility, and pain. The condition can be debilitating and require intensive, costly treatment (Ryan et al, 2003; Tiwari, 2003). As the condition is irreversible, patients with, or at risk of developing, lymphoedema require care throughout their life.

Prevention and early intervention are two of the main issues in lymphoedema care (Paskett et al, 2012). Precise assessment of the condition is important for timely intervention and to prevent worsening of the patient’s condition. In many cases, lymph transport impairment is only suspected after the reporting of discomfort, by which time a severe condition has often developed (Weisleder and Schuchhardt, 2008).

Preventing lymphoedema following cancer treatment is an important issue with long-term health costs. Preventive education for postoperative patients with gynaecological, prostate, or breast cancer with LND in Japan is provided twice by national health insurance; perioperatively on admission for surgery, and within one month of discharge.

A reliable predictive index for the onset of lymphoedema that enables early intervention and preventative care is required.

Multiple frequency bioimpedance analysis (MF-BIA) is a noninvasive method used in various clinical settings to estimate body fluid (Bellizzi et al, 2006; Mager et al, 2008). In recent years, MF-BIA has been applied to the quantification of lymphoedema (Hayes et al, 2009; Loudon et al, 2012). The technique is based on different conductive and resistive properties when a small electric current is applied to tissues in vivo (Ackland et al, 2004).

At low frequencies, most of the current will flow preferentially through the extracellular fluid (ECF). In contrast, reactance of the cell membranes decreases at higher frequencies, and the current passes through both the ECF and intracellular fluid (ICF; Dittmar and Reber, 2002). The ratio of the body water component ECF/ICF or ECF/total body fluid (TBF) is widely used to assess fluid changes in oedematous patients, including those with lymphoedema.

Sakuda et al (2010) showed the characteristics of body fluid by ICF/ECF in breast cancer patients after surgery (Sakuda et al, 2010). Some studies have shown the success of using MF-BIA as a tool to predict the early onset of lymphoedema (Cornish et al, 2001; Halaska et al, 2010). However, there is currently no reliable index to predict the occurrence of lymphoedema.

The aim of the present prospective study was to detect the potential occurrence of secondary lymphoedema due to LND by examining...
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variance in the body water composition of patients’ lower limbs before, and during the early stages after, LND.

Methods
A prospective, single-centre, observational, preliminary study of two groups of patients who had undergone gynaecological surgery, with or without LND, was conducted between February and September 2011.

Settings
This study was conducted in the outpatient department of the gynaecology unit and the outpatient department of the lymphoedema care ward at a university hospital in the Tohoku region, Japan.

Sample
Patients scheduled to undergo gynaecological surgery were potential candidates for the study, except those who were diagnosed with primary lymphoedema or had other oedema-related episodes (e.g. kidney, liver, or circulation disorders). Patients were divided into two groups according to whether or not they had undergone LND: a LND group, and a control (CONT) group, respectively.

Procedure
Patients were recruited on the date of admission. The first examination (pre-OPE) was conducted after informed consent was obtained, and the second examination was conducted on the seventh day postoperatively (POD7), after the patient’s general condition was stable and after all drainage, intravenous drips, and staples had been removed. Due to the circadian variation in body water, measurements were conducted between 2pm and 4pm local time.

Assessment of lower-limb conditions
The circumference of each lower limb was measured at the following seven locations with a plastic measuring tape: acrotarsium (mid-foot); immediately above the ankle joint; 10 cm distal to the patella; directly above the patella; 12 cm and 20 cm proximal to the patella; and at the uppermost part of the lower limb (Figure 1).

MF-BIA
For taking body water measurements a bioimpedance spectrometer was used. Before the examination, patients urinated and removed jewellery. Patients wore hospital gowns or clothes without any metallic accessories. The measurement took place with the patient in the supine position after a minimum of 5 minutes rest. Both upper limbs were positioned away from the body trunk, and the thighs were opened to about 30°. The ratio of ECF to TBF (E/T) was then calculated. The “eight electrodes method” (Bosy-Westphal et al, 2013) was employed to measure the fluid content of the whole body and also specific body parts (i.e. right/left upper limb, body trunk, and right/left lower limb).

For healthy individuals, E/T values of 0.36 to 0.40 are expected; higher E/T values indicate an increase in TBF (Van Loan and Mayclin, 1992; Kyle et al, 2004).

Table 1. Patient characteristics.

<table>
<thead>
<tr>
<th>Surgery type (LND)</th>
<th>Lymph node dissection (n=14)</th>
<th>Control (n=7)</th>
<th>Z-value</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>Mean±SD</td>
<td>Median</td>
<td>Mean±SD</td>
<td>Median</td>
</tr>
<tr>
<td>Age (years)</td>
<td>55.1±9.5</td>
<td>57.0</td>
<td>43.5±12.8</td>
<td>42.0</td>
</tr>
<tr>
<td>Height (cm)</td>
<td>158.0±7.3</td>
<td>158.0</td>
<td>156.1±7.1</td>
<td>155.7</td>
</tr>
<tr>
<td>Weight (kg)</td>
<td>58.5±9.3</td>
<td>57.6</td>
<td>67.7±23.4</td>
<td>57.0</td>
</tr>
<tr>
<td>BMI (kg/m²)</td>
<td>23.5±3.5</td>
<td>22.9</td>
<td>27.9±10.5</td>
<td>26.5</td>
</tr>
<tr>
<td>Cancer type</td>
<td>N %</td>
<td>N %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cervical</td>
<td>3 21.4</td>
<td>1 14.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uterine</td>
<td>10 71.4</td>
<td>2 28.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ovarian</td>
<td>1 7.1</td>
<td>1 14.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other / unknown</td>
<td>-</td>
<td>3 42.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>%</td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pelvic lymphadenectomy</td>
<td>1 7.1</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paraortic lymphadenectomy</td>
<td>13 92.9</td>
<td>-</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Results
Twenty-one patients (LND n=14; CONT n=7) participated in the study. The key demographic, diagnostic, and treatment characteristics are detailed in Table 1. They were: cancer of the cervix (LND, n=3; CONT, n=1), cancer of the uterus (LND, n=10; CONT, n=2), cancer of the ovary (LND, n=1; CONT, n=1), and three other diseases (myoma, ovarian tumour, and choriocarcinoma) in the CONT group.

The extension of LND in the LND group comprised one case of pelvic lymphadenectomy and 13 cases of paraaortic lymphadenectomy. In the CONT group, all patients underwent abdominal total hysterectomy (ATH, n=1) or ATH and bilateral salpingo-oophorectomy (BSO, n=6). Two patients in the LND group were unable to participate in the study on POD7 due to their still receiving an intravenous drip, and one patient in the CONT group was discharged early and therefore missed participation.
the POD7 measurement. Twelve patients in the LND group and six patients in the CONT group completed the study, and their data were subsequently analysed. No significant differences in age, height, weight, or body mass index were identified between the LND and CONT groups by Wilcoxon’s test. Two patients from the LND group reported an oedematous condition around their vulva on POD7, which was confirmed by their physician. No other swelling was reported by these two patients or by any other patients in the study.

Weight and circumferential changes
No significant differences were observed between the LND and CONT groups at either examination. An unexpected, but significant, decrease in circumference 12 cm distal to the patella on both legs (P=0.013) in the LND group was seen between pre-OPE and POD7 (Table 2). No significant differences in circumferential measurements were observed in the CONT group.

Bi impedance analysis
The LND group showed a significantly higher E/T than the CONT group in the body trunk on POD7 (P=0.04). No significant differences in other regions of the body were observed.

Table 2. Circumference measurement of the lower limb preoperatively (pre-OPE) and seventh day postoperatively (POD7) in the lymph node dissection group (n=12).

<table>
<thead>
<tr>
<th>Region</th>
<th>Pre-OPE (cm)</th>
<th>POD7 (cm)</th>
<th>Z-value</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean±SD Median</td>
<td>Mean±SD Median</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight (kg)</td>
<td>59.3±9.8 Median 57.6</td>
<td>58.4±9.3 Median 57.0</td>
<td>0.84</td>
<td>0.401</td>
</tr>
<tr>
<td>Right leg</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Acrotarsium</td>
<td>21.1±1.1 21</td>
<td>21.0±1.1 20.7</td>
<td>0.41</td>
<td>0.681</td>
</tr>
<tr>
<td>2. Ankle</td>
<td>20.3±1.7 20</td>
<td>19.9±1.5 19.5</td>
<td>1.20</td>
<td>0.229</td>
</tr>
<tr>
<td>3. 10cm lower patella</td>
<td>34.2±2.5 34.4</td>
<td>33.4±2.1 33.5</td>
<td>1.65</td>
<td>0.100</td>
</tr>
<tr>
<td>4. Patella</td>
<td>33.5±2.9 32.8</td>
<td>33.0±2.9 32.6</td>
<td>0.40</td>
<td>0.688</td>
</tr>
<tr>
<td>5. 12cm upper patella</td>
<td>41.5±3.7 40.4</td>
<td>40.4±3.4 39.7</td>
<td>2.49</td>
<td>0.013</td>
</tr>
<tr>
<td>6. 20cm upper patella</td>
<td>47.9±4.2 48.2</td>
<td>47.2±4.2 47.6</td>
<td>1.91</td>
<td>0.056</td>
</tr>
<tr>
<td>7. Upper most</td>
<td>51.9±5.2 52.45</td>
<td>51.9±5.3 51.7</td>
<td>1.07</td>
<td>0.283</td>
</tr>
<tr>
<td>Left leg</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Acrotarsium</td>
<td>21.0±1.1 20.8</td>
<td>20.8±1.1 20.4</td>
<td>1.43</td>
<td>0.514</td>
</tr>
<tr>
<td>2. Ankle</td>
<td>20.2±1.8 19.8</td>
<td>19.7±2.3 19.5</td>
<td>1.23</td>
<td>0.218</td>
</tr>
<tr>
<td>3. 10cm lower patella</td>
<td>33.8±2.4 34.4</td>
<td>35.7±2.5 32.5</td>
<td>1.79</td>
<td>0.074</td>
</tr>
<tr>
<td>4. Patella</td>
<td>33.4±2.9 32.9</td>
<td>32.7±2.7 32.7</td>
<td>1.21</td>
<td>0.228</td>
</tr>
<tr>
<td>5. 12cm upper patella</td>
<td>41.3±3.6 41.7</td>
<td>40.1±3.7 40.4</td>
<td>2.49</td>
<td>0.013</td>
</tr>
<tr>
<td>6. 20cm upper patella</td>
<td>47.5±4.4 47.8</td>
<td>46.5±4.0 47.6</td>
<td>2.27</td>
<td>0.023</td>
</tr>
<tr>
<td>7. Upper most</td>
<td>51.9±5.3 52.3</td>
<td>51.6±4.7 52.3</td>
<td>2.81</td>
<td>0.412</td>
</tr>
</tbody>
</table>

Table 3 provides a summary of the E/T of the body fluid in each region at each examination. In the LND group, POD7 E/T was significantly higher than that of pre-OPE in the body trunk (P=0.003) and right lower limb (P=0.005).

No significant differences between the two groups were seen throughout the measurement term (pre-OPE to POD7). Measurements in the upper limb indicated significant changes in E/T.

Discussion
This study revealed changes in the lower limb during the early phase after gynaecological surgery with LND. Patients who had LND showed a change in E/T in the right lower limb and trunk, although subjective symptoms were reported in only few cases (Table 3). This finding indicates that body fluid changes could be detected before the symptomatic awareness. Cornish et al (2001) have previously made this point by using the MF-BIA technique in breast cancer patients, however, there are limited studies relevant to gynaecologic cancer-related lymphoedema.

After gynaecological cancer surgery with LND, swelling is often clinically observed in the genital and inguinal region and can extend to other regions, such as the upper and lower limbs. Our results are compatible with these observations. The changes were only observed in the right lower limb. This might be due to the short follow-up period (7 days) and small sample size, which are limitations of this study. The short-term and unexpected trend in decreasing circumference 12 cm and 20 cm proximal to the patella in the LND group (Table 3) could also be due to the limitations of the study.

A previous retrospective study showed that 75% of postsurgical lymphoedema cases occur within one year (Beesley et al, 2007). In another retrospective study, Tada et al (2009) reported that secondary lymphoedema of the lower limbs can be observed at a mean of 4.2 months after the surgery but can occur as early as 0.1 month. Prospectively, monitoring parameters related to lymphoedema presurgery would allow detection of subtle changes before patients are aware of their symptoms, allowing early intervention.

The MF-BIA was used to monitor one of these parameters in the present study, Halaska et al (2006) also used this method to prospectively assess patients for lymphoedema 3 months before and 6 months after surgery for uterine cervical cancer. They reported a 47.6% prevalence of lymphoedema 6 months after surgery. Since lymphoedema has been reported in some studies as early as 0.1 month after surgery, it is reasonable to assume that some changes would have occurred 3 months after surgery. This would be consistent with the subtle changes the authors observed in the lower limbs after only a week (POD7).

This short-term study does not include any of the effects of adjuvant therapy, such as radiotherapy, which is reported to increase the risk of lymphoedema (Tada et al, 2009). Therefore, the authors propose follow-up of parameters related to lymphoedema (particularly changes in body fluid) before and as early as possible after surgery to avoid missing the opportunity for timely treatment.

Early detection and management of lymphoedema have another benefit; reducing the potential risk of infection and hospitalisation in the longer term. Chronic oedema is a known risk factor for cellulitis, which can become recurrent after a single soft tissue infection (Swartz, 2004). Cox (2006) also found that there is a strong association between oedema and cellulitis, each of which is both a risk factor for, and
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Table 3. Extracellular fluid to total body fluid of the lower limb preoperatively (pre-OPE) and seventh day postoperatively (POD7) in the lymph node dissection (LND; n=12) and control (n=6) groups.

<table>
<thead>
<tr>
<th>Group</th>
<th>Pre-OPE</th>
<th>POD7</th>
<th>Z-value</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean±SD Median</td>
<td>Mean±SD Median</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LND group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Right upper limb</td>
<td>0.377±0.005   0.379</td>
<td>0.377±0.045   0.376</td>
<td>0.717</td>
<td>0.474</td>
</tr>
<tr>
<td>2. Left upper limb</td>
<td>0.3799±0.003  0.381</td>
<td>0.3799±0.003  0.379</td>
<td>0.760</td>
<td>0.447</td>
</tr>
<tr>
<td>3. Body trunk</td>
<td>0.39±0.005    0.384</td>
<td>0.3927±0.005  0.391</td>
<td>2.936</td>
<td>0.003</td>
</tr>
<tr>
<td>4. Right lower limb</td>
<td>0.3919±0.008  0.387</td>
<td>0.3919±0.008  0.391</td>
<td>2.807</td>
<td>0.005</td>
</tr>
<tr>
<td>5. Left lower limb</td>
<td>0.39±0.007    0.387</td>
<td>0.3904±0.007  0.389</td>
<td>1.423</td>
<td>0.311</td>
</tr>
<tr>
<td>6. Total body</td>
<td>0.39±0.005    0.385</td>
<td>0.3905±0.005  0.388</td>
<td>2.807</td>
<td>0.005</td>
</tr>
<tr>
<td>Control group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Right upper limb</td>
<td>0.377±0.003   0.379</td>
<td>0.3770±0.006  0.377</td>
<td>0.365</td>
<td>0.715</td>
</tr>
<tr>
<td>2. Left upper limb</td>
<td>0.3785±0.003  0.379</td>
<td>0.3784±0.005  0.379</td>
<td>0.406</td>
<td>0.684</td>
</tr>
<tr>
<td>3. Body trunk</td>
<td>0.3782±0.007  0.381</td>
<td>0.3830±0.009  0.386</td>
<td>1.753</td>
<td>0.080</td>
</tr>
<tr>
<td>4. Right lower limb</td>
<td>0.3777±0.009  0.380</td>
<td>0.3798±0.016  0.385</td>
<td>0.813</td>
<td>0.416</td>
</tr>
<tr>
<td>5. Left lower limb</td>
<td>0.3820±0.009  0.387</td>
<td>0.3870±0.100  0.387</td>
<td>1.483</td>
<td>0.138</td>
</tr>
<tr>
<td>6. Total body</td>
<td>0.3788±0.007  0.382</td>
<td>0.3826±0.103  0.385</td>
<td>1.355</td>
<td>0.176</td>
</tr>
</tbody>
</table>

Consequence of the other. Reducing oedema is effective in reducing cellulitic episodes, however, prevention of lymphoedema through early intervention may be the most effective prevention of cellulitis.

The authors are mindful that the swelling of limbs in the early phase following surgery is a temporary symptom (Moore, 1958; Wilmore, 2002) and secondary lymphoedema is often a late manifestation; a longer follow-up period is needed to predict the occurrence of lymphoedema. However, assessment and understanding of swelling or oedematous symptoms following surgery is important and may better inform our understanding of the clinical course of lymphoedema.

In the future, the authors intend to extend the observation period to prospectively monitor the spread of lymphoedema to other regions of the body and to elucidate the clinical course of lymphoedema in this patient population.

Conclusion

Body water changes were observed in the early postoperative phase in LND patients. MF-BIA is one of the tools for detecting potential early changes, even before the appearance of subjective symptoms. The methodological feasibility of this study has opened up the possibility of further studies on lymphoedema.

Acknowledgements

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References

Evidence and tradition in conflict: The Swedish experience of lymphoedema treatment and care

Polymnia Nikolaidis, Katarina Karlsson

Key words
Lympheoedema therapist, patient expectation, communication, patient organisation

Abstract
The basis of Swedish lymphoedema treatment programmes were first developed in Germany early last century. The treatment principles remained the same until recent years and are based on manual lymph drainage, compression, skin care, and exercise. However, our experience is that it is important to assess patients holistically and therefore other approaches to treatment may be better. We suggest that less emphasis be placed on manual lymph drainage and more on compression, exercise, and weight reduction.

Key words
Lymphoedema therapist, patient expectation, communication, patient organisation

In a developed country like Sweden, patients generally present early, the oedema volume is usually low, and oedema is mainly related to cancer treatment. Knowledge of cancer-related oedemas is important. These are often recognised at an early stage and the lymphoedema treatment is an integrated part of rehabilitation.

However, access to care may vary, particularly due to geography and clinician availability. The goal of lymphoedema treatment is not only to reduce and/or improve function, but also to improve patients’ quality of life and – for those at risk of developing lymphoedema – deliver education on prevention.

Lymphoedema therapists are generally fully responsible for initiating and evaluating the lymphoedema treatment plan. This includes the ordering and fitting of compression garments and stockings. This is an advantage as the therapist follows the person from diagnosis to endpoint and can continue to monitor, manage, and evaluate the patient.

Follow-up visits with patients after lymph node surgery are routine. This includes patients with malignant melanoma. Patients are provided with preventive information early (usually the day after surgery) and are normally followed-up 4–5 weeks later by a physiotherapist/lymphoedema therapist, either individually or in a group.

At the follow-up visit, an assessment of joint mobility is conducted and the patient is informed about the basic functioning of the lymphatic system, skin care, and the importance of performing some kind of physical activity. These individuals are encouraged to begin their physical activities as soon as possible, preferably 2–3 weeks postsurgery.

People who were previously physically inactive are advised to take up some kind of exercise for the upper body – such as swimming, pole walking (Nordic walking), weight lifting, cross country...
skipping, or rowing—in order to stimulate the lymphatic and blood circulation. In the case of inguinal clearance, cycling and swimming are recommended. At this visit the therapist will measure the limb and order compression stockings or sleeves, in case oedema should develop.

There are many benefits of early diagnosis and treatment (Ramos et al, 1999; Johansson and Branje, 2010). Patients can either eliminate minor oedema or reduce it to a level that does not affect their activities.

In terms of rehabilitation, at Karolinska University Hospital in Stockholm, patients are educated to recognise the early signs of lymphoedema and usually present early with minimal oedema (stage 0–2).

For breast cancer patients, compression garments or bandaging are recommended for a few days in most cases to reduce oedema, if needed, and thereafter measure and fit a compression garment.

Manual lymph drainage (MLD) performed by the lymphoedema therapist is never the first choice of treatment. Patients are informed about the lack of evidence for MLD, but are encouraged to undertake self massage for a short period to evaluate its effects. Where self massage is ineffectual, the patient can discontinue and focus on wearing compression garments and being physically active. Patients are encouraged to begin some form of exercise for improving circulation (Schnitz et al, 2010; Kwan et al, 2011).

In cases of advanced cancer, the treatment plan is different and depends on factors such as venous obstruction, medication-related oedema, levels of plasma protein, activity, oncological treatment, and oedema status. Treatment is mainly aimed at improving function and comfort.

**Treatment expectations**

Patients may have different goals, motivations, and expectations of treatment. For a patient with high levels of oedema, a reduction in oedema may mean that they can return to work, for another, even a small volume of oedema may negatively impact self confidence and self esteem with the accompanying psycho-social consequences. Thus, patient expectations may not always coincide with the lymphoedema therapist’s goals and expectations of treatment.

**A shift in care**

Traditionally, the main outcome measure of successful lymphoedema treatment has been reduced oedema volume. Treatment has been focused on MLD. However, based on more recent research, a paradigm shift in therapy is underway. In the future, therapists will most likely emphasise holistic care, favouring compression therapy and physical activity over MLD.

In recent years, there has been contradictory evidence of the value of MLD. Research is not always convincing, and MLD has not proven to reduce the volume of lymphoedema (Kärki et al, 2009; Huang et al, 2013).

Physical activity in cancer care is important because it has been shown to reduce the side effects of treatment (e.g. pain, fatigue, and nausea) and improve quality of life, physical strength, and mobility (McNeely et al, 2006). Lymphoedema therapists need to examine how we can accelerate change in our approach to oedema management and how this should be integrated into health care systems.

**Patient responsibility**

The level of responsibility the patient is expected to take is different around the world. In some countries, the patient is passive—they expect the therapist to take full responsibility for their oedema treatment and they will place themselves in the hands of the therapists. In other countries, emphasis is given to the patient accepting responsibility for their treatment and the therapist has a more guiding role.

A good clinical outcome is more likely to be achieved if the therapist and patient agree on treatment goals and the patient’s obligations (i.e. some form of contract exists). The therapist must be clear about what is required of the patient and encourage them to ask themselves: “What have I done for my oedema/limb today?”

It is also important to enhance and reinforce the patient’s ability to cope with everyday oedema care, which may be troublesome for some people (Piller, 2012). Some oedemas are complex and this is particularly true of lower-limb oedema. Few secondary lymphoedemas are solely of lymphatic origin and there is usually venous insufficiency present to some degree. This means that patients respond differently to both compression and physical activity.

Often the lymphoedema therapist has to assess which therapies work best for the individual. At times, it can be a “try and see” approach, where one change is made at a time and its effect is measured.

Primary lymphoedema is relatively rare and commonly underdiagnosed, which contributes to the fact that this group of patients usually presents at a later stage than those with oedema related to breast cancer treatment. This late presentation makes the treatment more extensive and difficult and is compounded by the lack of doctors specialising in lymphoedema. This often means that a complicated patient is assessed solely by a lymphoedema therapist. Experience is critical in providing targeted and appropriate treatments to optimise outcomes. Fortunately, complex cases are becoming rarer, since knowledge about lymphoedema and its treatment are becoming more well known.

However, in Sweden, the authors know from experience that many newly trained lymphoedema therapists often do not have access to patients’ medical records and do not have an experienced supervisor or mentor to ask for advice. This can compromise patient care and result in suboptimal treatment.

A further problem is that a physical therapist or lymphoedema therapist working in primary care will mainly treat other groups of patients, such as those with orthopedic, neurological, or muscle-related disorders. The therapist may actually assess, treat, and follow-up very few lymphoedema patients. It may take many years to gain clinical experience of the various types of oedemas and lymphoedemas, and of the optimal treatments. In an oncology setting, this does not pose such a problem as many patients are similar in terms of their treatment and present for therapy relatively early.

**Education issues**

Some lymphoedema therapist education programmes are short (sometimes only a few days in duration) and their targets are primarily cosmetologists and beauticians. In Sweden, longer courses (4–6 weeks) are only open to clinicians such as physiotherapists, nurses, and occupational therapists.
Nonetheless, the therapist in the shorter education programmes will often receive a certificate stating that they have received some degree of lymph therapist education. In Sweden, holding this type of certificate can mean a clinician is allowed to treat patients with secondary lymphoedema. Often this leads to people treating patients without possessing any basic knowledge of oncology or pathophysiology. Ideally, no person without a basic clinical qualification should be accepted for a lymphoedema therapy training programme.

The title “lymphoedema therapist” is not one of the professions covered by the Patient Safety Act in Sweden. This means that while lymphoedema therapists with no medical qualifications are not allowed to work and treat patients within the public healthcare system, they can still treat lymphoedema patients at private clinics. This must be borne in mind to ensure the limitations of knowledge and practice can be addressed.

As previously mentioned, therapists’ backgrounds vary and so does their therapeutic focus. For example, in England, nurses initially treat lymphoedema patients, and their main focus is on the skin and skin-related issues. While in Sweden, for the most part, physiotherapists treat lymphoedema. Therefore, the body’s musculoskeletal system and function and activity limitations are focused on. Fewer skin problems are also encountered by clinicians since patients are treated earlier in the process.

Self-care is key
The significance placed on physical activity in the treatment of lymphoedema in Sweden means that a large proportion of patients are required not only to take care of their skin and compression therapy, but also to exercise regularly. Thus, patients spend a lot of time managing their oedema treatment.

The lymphoedema therapist’s role in treatment is to guide, motivate, and empower patients, helping them take an active role in treating their oedema.

From clinical experience, the authors note that many patients choose to end their contact with the lymphoedema therapist. The reasons may vary, and we know from experience that some early oedemas decrease with time or disappear completely and so the patient no longer needs or seeks any input from the lymphoedema therapist.

Some patients who have low volume oedemas request regular MLD. Those who live in the Stockholm area are able to receive such treatment from the many lymphoedema therapists in the city. Unfortunately, the wide availability of lymphoedema therapists may mean that some patients are over-treated with MLD, use compression when they do not actually need it, or become dependant on the lymphoedema therapist rather than independent.

Patients are sometimes frustrated when they cannot receive MLD in the way they did earlier in their treatment, or from what they know other similar patients have received. People also want other complementary techniques, such as laser therapy, compression pumps, and other methods they have heard about. Therefore, some patients are sometimes disappointed that the healthcare system is too evidence-based and does not use supplementary methods to the extent they would like.

This leaves a number of important questions unanswered. Is it outcomes other than reduced oedema volume that some patients expect from treatment? How well can lymphoedema therapists meet these patients’ needs? Is the patient asking for MLD for reasons other than oedema/volume reduction? Is it perhaps the touch/tactile stimulation or the soothing effect of the MLD? Should this additional demand be met by lymphoedema therapists, or should these patients seek a private massage therapist?

A new approach to care
We need to consider if therapists need to be more holistic in their approach and integrate and accept other professions into the management of the patient. For instance, in some circumstances, could cognitive behavioural therapy help the patient better handle cancer, the impacts of its treatment, and the symptoms of the lymphoedema? Perhaps body awareness training, mindfulness, or yoga might help?

Patients frequently seek out patient organisations to meet other people in the same situation, gain knowledge from other patients’ experiences, actively questioning treatments, share their collective knowledge of oedema, and often, importantly, what others think of available therapists. An important part of the work of these organisations is, therefore, to provide objective and evidence-based information to their members as well as convey to them the fact that not every method is appropriate in every case.

The research into lymphoedema treatment is limited. Not every therapy has a high level of evidence and there will often be contradictory reports. Presenting and acknowledging the balance is critical in ensuring therapists, patients, and patient organisations work together for the best outcomes. Communication is a critical part of this process. The interaction between the lymphoedema therapist and these organisations needs examining.

Conclusion
Lymphoedema treatment in Sweden is not perfect, but there is a great opportunity to make it better. A paradigm shift in treatment can more easily be implemented by greater holistic thinking and working in close cooperation with patient organisations.

References


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Use of a two-layer compression system in severe bilateral leg lymphoedema with ulceration: A case report

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Key words
Chronic ulcer, compression, lymphoedema, wound healing

Abstract

Background: In this case report the authors present an individual with a medical history of severe bilateral leg lymphoedema, multiple bilateral ulceration, type 2 diabetes, and morbid obesity. Aim: To determine the efficacy of a commercially available compression system (Coban™ 2 Compression System; 3M) on an individual with severe bilateral leg lymphoedema, and multiple bilateral ulceration. Methods: Employing the Coban 2 Compression System toe-boot bandaging technique, objective and subjective data on leg volume, tissue compositional changes and wound healing were collected at baseline and three times per week over a 4-week follow-up period. Under-bandage pressures were controlled using a pressure monitor during bandage application. Results: The patient’s total limb volume decreased during treatment; circumference volume measurements showed a 3 L reduction in the left leg, and a 1.3 L reduction in the right leg. Limb volume decreased by 2.1 L in the left leg, and 2.1 L in the right. Bioimpedance spectroscopy data measured a reduction of 3.2 L in the left leg and 3.0 L in the right leg. Tissue fluids reduced by 55% in the superficial tissue of both calves during the intervention period. The reduction of the total wound size was 21.7 cm² in the left leg and 19.95 cm² in the right leg. Conclusion: Treatment with Coban 2 Compression System improved wound healing and decreased leg volume in the present case.

Research into the benefits of compression on venous congestion and associated ulceration has been widely documented (Milic et al, 2010; Stucker et al, 2013). However, research into the correct level of compression for lymphoedema is difficult to obtain, most likely due to a lack of inclusion of rigorous undergarment pressure measurements in reports. The preferred method of lymphoedema treatment is usually compression of the limb, due to its ability to enhance venous return, reduce capillary filtration, and increase lymphatic reabsorption and the breakdown of fibrotic tissue (Moffatt et al, 2011; Muldoon and Charles, 2013).

It is vital that, during the intensive treatment phase for lymphoedema, the compression garment does not hinder an individual’s range of movement to ensure maximum lymph flow from the affected area. It has been documented that muscle contraction while wearing compression produces a higher peak in blood and lymph flow velocity (Partsch and Moffatt, 2012). The Coban™ 2 Compression System (3M) is a two-layer, latex-free, self-adherent compression bandage. Its rigidity and inelastic properties ensure a high working pressure and low resting pressure. The Coban 2 Compression System has been shown to be useful in lymphoedema reduction and venous ulcer healing in multicentre, randomised, controlled trial settings (3M, 2011; Moffatt et al, 2011; Morgan et al, 2011). These studies account for the user-friendliness of the application for the clinician, as well as monitoring slippage, patient comfort, and mobility.

The burden of chronic wounds
Chronic nonhealing wounds frequently occur in the latter stages of lymphoedema. They are especially problematic in the lower legs due to their dependency. Chronic wounds can be costly and are a major public health problem in addition to significantly reducing the quality of life of the affected person (Agale, 2013). A high incidence of venous ulcers and recurrence has been reported within the Australian community (Barker and Weller, 2010). Chronic leg ulcers are believed to affect more than 3% of the population aged ≥65 years, with a 56% chance of reoccurrence within 3 months of healing (Barker, 2010).

Case study
A 61-year-old Caucasian male (Patient X) presented at the Lymphoedema Research Unit at Flinders University in April 2013 with severe bilateral lymphoedema, that had persisted since 2009. He had received several intensive reduction treatments since that time; however, due to high treatment costs, he ceased them in early 2011. The patient reported that in March 2008 he had multiple fibromas removed from the groin. The fibromas penetrated deeper than initially anticipated. Within 2 days of surgery, the postoperative deep tissue wounds had become infected, and the participant was admitted for multiple daily dressing changes. Three days later, the wounds showed signs of continued breakdown and an increase in necrotic tissue. Patient X was immediately admitted to...
emergency surgery to prevent the spread of gangrene. The extent of soft tissue trauma, major infection, and possibly lymphatic vessel disruption is likely to have evoked the onset of lymphoedema in 2009.

In October 2012, a lymphoscintigram showed functional lymphatic insufficiency, but no indication of dermal backflow. Lymph drainage from both legs was within normal limits. Deep vein thrombosis was discounted and a chest X-ray did not show overt cardiac failure.

With a history of morbid obesity, hypertension, and type 2 diabetes, the skin on the patient’s lower legs showed signs of dryness, fissures, and weeping ulcers. He also suffered recurrent episodes of erysipelas, further compounding the lymphoedema. A lower-back injury prevented him from wearing a compression garment. To manage his condition and to respond to frequent flare ups, he visited the emergency department on a weekly basis for dressing changes and antibiotics, if needed. Wound dressings alone did not facilitate wound healing, with limb volumes and his wounds continuing to worsen, so it was decided that an intensive compression therapy programme would be initiated, with the main aims being to reduce lymphoedema and associated wound discomfort.

Clinical presentation lymphoedema

Patient X presented with extremely dry and scaly skin, and pitting on the lower legs and dorsal surfaces of both feet. The upper legs and knees seemed unaffected and bilateral positive Stemmer’s sign was present. Skin changes, hyper pigmentation on both lower limbs, papillomatosis on the base of the toes, and fibrotic tissue in the mid area of the tibia (bilateral) were also present. The limbs were categorised as stage III lymphoedema, as per International Society of Lymphology consensus (2009). There were no signs of neuropathy, despite the individual having diabetes.

Patient X is retired and resides with his sibling. He explained he is very fond of computer games and can spend hours sitting on a computer chair without laying supine for a night’s rest.

Both legs had multiple wounds with excess yellowish-clear exudate. Granulation tissue was visible, but all wounds were covered with debris and showed signs of infection (Figure 1).

Materials

Patient X’s lower legs were bandaged using a toe-boot application with the Coban 2 Compression System. This intervention was applied every second day for a duration of 4 weeks due to leakage of the wound areas.

The following bilateral duplicated measurements were obtained at every clinic visit:

- Wound size and perimeter using a Visitrak wound measurement grid (Smith & Nephew).
- Limb circumferences using a Perometer 350S (Pero-System Messgeräte) every 3.7 mm and a standard tape measure every 4 cm.
- Total body water (intracellular and extracellular), limb fluid volumes, fat and muscle masses using a whole-body Bioimpedance Spectroscopy Unit (InBody).
- Site-specific tissue fluid (MoistureMeter D; Delfin Technologies).
- Undergarment pressure in supine position (Kikuhime; mediGroup) on the lateral side of lower limb, large probe.
- Transdermal water loss (TEWL; VapoMeter).
- Tissue resistance using an indurometer (Flinders Biomedical Engineering).
- A quality of life questionnaire was also completed and photos taken (Keeley et al, 2010).

Methods

Patient X’s lower legs, including the feet and toes, were cleansed with lukewarm water and a surgical sponge (Medisponge, Filtrona Porous Technologies) and dried prior to all measurements being taken. The limb was then bandaged with Coban 2 Compression System, using the toe-boot application method (3M, 2011). Bandage slippage was monitored with a simple mark on the skin with a marker pen and measured with measuring tape upon return appointments. While applying bandages in the supine position, 42 mmHg–45 mmHg was required to reach the desired 50 mmHg of under-bandage pressure when standing.

Site-specific tissue fluid was measured at anterior mid-thigh (15 cm proximal from patella), posterior mid-thigh (15 cm proximal from knee crease), and posterior lower limb (15 cm distal from knee crease). A bilateral dorsal site measurement was also taken (medium probe, 2.5 mm–5 mm in skin), 5 cm from the base of the toes using the MoistureMeter D.

Results

Treatment with the Coban2 Compression System over 4 weeks significantly decreased Patient X’s total limb volume. During the active bandaging time (between baseline and final visit) limb volume as measured by the Perometer was reduced by 2.1 L in the left leg and 2.1 L in the right leg. The right leg increased in volume from week four to follow up by 0.4 L and the left leg increased by 0.1 L, which was expected as active intervention had ceased.

Lower extremity total volumes were calculated from the circumference measurements using the truncated cone formula; a limb volume reduction of 3.1 L in the left leg and 1.7 L in the right leg was observed. During the active bandaging period (4 weeks), the Bioimpedance Spectroscopy (InBody) measurement showed a reduction of 3.2 L in the left leg and 3.0 L in the right leg. At the follow-up appointment, further fluid reduction was measured, despite no active intervention (Patient X was wearing bilateral compression garments).

Multiple wounds were present bilaterally, on the distal posteriors of the lower limbs. At baseline, the left leg had a total wound size of 25.8 cm² and right leg was 29.7 cm². Patient X’s wound size reduced by 21.7 cm² in the left leg and 17.7 cm² in the right leg between baseline and final visit. It was observed at follow up (4 weeks post treatment) that no wounds were present on the left leg, while the right leg wounds had continued to decrease in size by 2.25 cm², giving a total reduction of 19.95 cm² (Figure 2).

The TEWL readings fluctuated during the taking of measurements. This could be due to
the bandaging material being removed and cleansing of the legs before the measurements were taken. The authors waited for the skin to cool and dry, however, the lower limbs were often damp with perspiration. Higher TEWL readings in the right leg suggested a loss of barrier function. This was consistent with the authors’ prediction, as the wounds on the right leg were larger and harder to heal than those present on the left leg.

A 55% reduction in fluids in the superficial tissue of both calves (mean 34.4 units of calf area) was measured by MositureMeter D between baseline and final appointment. At the follow-up appointment it was noted that all fluid levels had increased again, which is to be expected given that the compression garment did not provide as high a pressure as the bandage did. A correlation was discovered between the thigh area measurement fluid increase and the indurometer data measured at baseline and follow up.

The indurometer showed a higher reading within the thigh areas, possibly indicating that fluid has been pushed up from the calf areas due to the compression bandaging and has made the upper-leg tissue softer. There were no significant indurometer findings at the other measurement sites (Figure 3).

Quality of life
There was no change in Patient X’s quality of life score over the case study period, with the participant rating 8 on a scale of 10 (0 = no quality of life, 10 = highest quality of life; Keeley et al, 2010). However, at week four, he reported less difficulty in areas such as walking, bending, and undertaking housework, in comparison to baseline. Patient X also reported that the swelling did not affect how he felt about himself “at all” by week four, compared to “a little” at baseline.

Overall, the Patient X reported an increase in ease of living from baseline to week four. However, at follow up, his answers were similar to baseline. At follow up, Patient X marked the same subjective scale numbers as baseline, however, he commented that his quality of life had improved. Patient X had “enjoyed coming for appointments” and discussing lifestyle and daily events with the researchers. The increase in quality of life throughout the treatment phase could be attributed to both the bandaging and the regular friendly contact of the authors. Patient X was compliant in wearing bandages throughout the 4-week treatment regimen. Although he reported some heat-induced discomfort at night, he found the bandages comfortable and noninvasive.

Conclusion
The compression bandaging used in this case report proved effective in reducing Patient X’s lymphoedema fluids, subsequently resolving his wounds. The removal of this fluid is essential for wound healing. Early detection is crucial to prevent further progression in lymphoedema, including skin breakdown and the appearance of chronic wounds. Cost is often a factor for both patient and clinician in treatment options and bandaging may prove a more cost-effective intervention that may halt wound progression. Bandaging must be applied correctly, with the right pressure and pressure gradient, and adapted to each patient’s needs, including mobility, comfort, and cost.

References
3M (2011) Training Manual Lymphoedema Intensive Therapy. 3M Health Care, Australia

Figure 2. Patient X’s (a) left and (b) right posterior leg wounds following 4 weeks’ treatment with the Coban™ 2 Compression System (3M).

Figure 3. Patient X’s legs at follow-up, (a) anterior and (b) posterior views.
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