

Head and neck lymphoedema management practices

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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

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).

- Surface tape measurements between facial landmarks can be used to evaluate HNL. Although tape measurements do not represent a volumetric measurement, they can be used to monitor progress over time. Some measurement systems only evaluate the face (Schultze-Mosgau et al, 1995; Piso et al, 2001), however, a combined facial and neck assessment may be preferable for HNL (Smith and Lewin, 2010).
- Digital photography is a simple way to record changes in HNL. Consistent distance, focus, and location should be used to allow photographs to be compared accurately over time (e.g. via use of wall markings or a string line between subject and camera).

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

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

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

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

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

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

Grade	Description
1	Localised to dependent areas and no disability or functional impairment.
2	Localised facial or neck oedema with functional impairment.
3	Generalised facial or neck oedema with functional impairment (e.g., difficulty in turning neck or opening mouth compared to baseline).
4	Severe with ulceration or cerebral oedema; tracheotomy or feeding tube indicated.

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® (Velcro Limited) attachment (Klose and Strößbenreuther, 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 pure 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

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 (Strößenreuther, 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 Strößenreuther, 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 Strößenreuther, 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 myofascial 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

for HNL, therefore a multifaceted approach is regularly employed. With no gold standard assessment available, those currently being used are inconsistent and, as a consequence, treatment outcomes are difficult to compare. Many assessments are not suitable for use in the clinical environment, which limits individual assessment of the outcomes of therapy. The future development of clinically accessible assessments for HNL is essential.

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