

# LYMPHOEDEMA IN PATIENTS TREATED FOR HEAD AND NECK CANCER

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Following surgery, radiotherapy and/or chemo-radiation for cancers affecting the larynx, oral cavity, pharynx, thyroid and salivary glands (collectively referred to as 'head and neck cancer' in this paper), patients are often left with persistent side-effects, one of which is the onset of lymphoedema which can increase their psychological distress and reduce functional ability. This paper explores the multi-dimensional, multidisciplinary approach to care within a rehabilitation programme, and indicates the importance of providing care in the context of the patient's physical and psychosocial needs.

## Key words

Head and neck cancer  
Lymphoedema  
Multidisciplinary team  
Rehabilitation

The treatment of head and neck cancer is complex, it can cause facial disfigurement together with other problems such as difficulty with breathing, swallowing, eating, drinking, speech, pain, normal social interaction and work (Data for Head and Neck Oncology [DAHNO], 2010). Where persistent side-effects to treatment exist, this can have a negative impact on the patient's quality of life, and for patients who subsequently develop secondary lymphoedema, this can present them with additional physical and psychological challenges.

This paper highlights some of the multiple factors that the lymphoedema nurse specialists, working in a nurse-led London clinic, consider when assessing, planning and implementing a rehabilitation treatment programme for this group of patients. In the context of

this article, patients affected by 'head and neck cancer' refers to cancers of the larynx, oral cavity, pharynx, salivary glands or the thyroid gland.

## Incidence

According to Cancer Research UK, 2010, the incidence of head and neck cancer in the UK accounts for 4–5% of all cancers, of these, 5,410 were oral cancers, 2,205 cancers of the larynx and 2,018 were thyroid cancers. Head and neck cancer tends to be more common in men than women, with 87% of patients being over 50 years of age (Cancer Research, 2010).

## Where head and neck cancer is treated

The Data for Head and Neck Oncology (DAHNO) 5th Annual Report for 2008–2009 (2010) states that 128 primary care trusts in England and Wales provide treatment for patients with head and neck cancer; with variations existing in the treatments offered. Although the document acknowledges that comorbidities have an impact on the outcome for patients, data was only received relating to comorbidities in 32% of all the cases reported. Lymphoedema is not listed as a comorbidity, nor does it state if lymphoedema services work directly with specialist head and neck centres.

The National Institute for Health and Clinical Excellence (NICE, 2004) recommends that treatment for head and neck cancer should be carried out

within specialist cancer centres, with patients being able to access a wide range of expertise (lymphoedema specialist services are not included). However, centralisation of services can make access for some patients difficult, and the report recommends that for economically deprived patients, and/or those who are too unwell to attend outpatient clinics, effective support should be provided within the community.

In the author's opinion, this highlights the need for services (in the UK) treating patients with lymphoedema secondary to head and neck cancer to work collaboratively to identify:

- ▶▶ The size of the problem
- ▶▶ Where patients can access treatment for lymphoedema
- ▶▶ Treatment options/programmes
- ▶▶ Gaps in services.

## Main risk factors associated with the development of secondary head and neck lymphoedema

### Surgery

Advances in the understanding of disease spread associated with head and neck cancer; together with changes in surgical techniques, have led to the introduction of less invasive surgery, including modified radical and selective neck dissection (March and Pinedo, 2009a). Lymph nodes are sandwiched between layers of fascia and divided into anatomical regions. Dependent on the site of the primary tumour, nodes are removed within

anatomical regions, at levels normally associated with the spread of disease.

In the head and neck there is a complex system of superficial and deep cervical lymph nodes and pathways that interconnect (Withey et al, 2001; Kubik, 2003). Due to the large number of interconnections within the lymph drainage system in this region of the body, with less invasive surgery, swelling will generally reduce after a period of a few weeks or months (Weissleder et al, 2008).

Removal of lymph nodes and vessels can trigger lymphoedema when lymph collectors cannot transport lymph away from the area at the same rate as it forms (Mortimer, 1995). If other lymph collectors are also compromised due to radiotherapy damage, this can increase the risk of the individual developing lymphoedema. At the present time, there is no agreed method of classifying the severity of lymphoedema for head and neck patients, (Lymphoedema Framework, 2006).

While we do not know the current incidence or severity of lymphoedema associated with head and neck cancer treatment, in the author's opinion it is likely to be more difficult to control where the patient has:

- ▶ Bilateral neck dissection — removal of the sternocleidomastoid muscle; internal jugular veins; accessory nerve and lymph nodes (Feber, 2000)
- ▶ Extended resection of soft tissue (for example, extending to the level of the mediastinum), and lymphadenectomy (Buckley, 2000)
- ▶ Recurrent cellulitis, which may cause further scarring and damage to the lymphatic system (Cooper and White, 2009)
- ▶ Advancing disease associated with increased obstruction within the lymphatic system
- ▶ Radiotherapy greater than 60 Gray, delivered in less than 25 fractions in less than four to five weeks (Edwards, 2000).

### Radiotherapy

Within the limitations of this paper, details about radiotherapy for head and neck cancers are not included. However, The Scottish Intercollegiate Guidelines

Network (SIGN, 2006) recommends postoperative radiotherapy be delivered 54–60 Gray in 27–30 fractions over 5.5–6 weeks. In areas of high risk, 66 Gray in 33 fractions over 6.5 weeks.

At 60 Gray, it is reported that the blood and lymph vessels become more permeable, increasing the amount of fluid and macromolecules that build up in the subcutaneous tissues (Mann et al, 1981, cited by Edwards, 2000). Over 60 Gray, the frequency of complications increases (March and Pinedo, 2009b). Where the length of time between the fractions is decreased, there is less time for the tissues to 'recover' between treatments, increasing the risk of further damage to the lymphatic system, fibrosis and associated lymphoedema.

Radiotherapy generally produces induration of the skin, most notably in the submental region; the normal transverse shape of the face means that this region receives the highest dose during radiotherapy (Edwards, 2000). In the author's clinical experience, examination of the submental area may reveal soft 'hanging' tissue with pitting oedema and underlying fibrosis, or the whole area may be 'woody' and fibrosed. In the author's experience, patients presenting with submental swelling have all commented on the distortion in shape. Examples of words patients used to describe submental swelling have included 'disfiguring', 'ugly' and 'turkey neck'.

### Medication

Steroids, and calcium channel blocking agents (the latter used to correct hypertension) may exacerbate swelling (Keeley, 2008). While it is acknowledged that it may not be possible for the patient to be prescribed alternative medication, in the author's opinion, an understanding of different factors (including pharmacological dynamics) that can influence head and neck swelling should be considered.

### Planning lymphoedema management

#### Working with the multidisciplinary team (MDT)

The impact of head and neck cancer treatment is complex, and patients can present with physical and psychosocial problems at any stage of their recovery. Therefore, effective, timely

communication across different disciplines is essential, if appropriate interventions are to be implemented that help prevent problems from developing into a crisis (Feber, 2000a).

In the author's clinic, lymphoedema is managed within the patient's overall treatment and rehabilitation programme, which necessitates close working with other members of the MDT. Each individual patient's response to their lymphoedema treatment is monitored, and any other physical or psychosocial problems identified during assessment are followed up. The patient is referred to the appropriate member of the MDT for further investigation when the problem lies beyond the expertise of the lymphoedema specialist, for example:

- ▶ Unrelieved and/or increasing intensity of pain
- ▶ Poor or no response to lymphoedema treatment
- ▶ Increased swelling
- ▶ Intra-oral infection and/or bleeding
- ▶ Musculoskeletal problem
- ▶ Withdrawal symptoms
- ▶ Increased anxiety/depression.

The role of the MDT (*Table 1*) is to coordinate care, and to ensure that patients receive timely access to appropriate healthcare professionals from the point of diagnosis through to completion of rehabilitation (NICE, 2004).

### Other considerations

With the lack of evidence to support best practice in the management of head and neck lymphoedema, current treatment is based on the:

- ▶ Patient's medical and psychosocial history
- ▶ Tumour node metastases staging, which provides an indicator of the risk of recurrence of disease (Feber, 2000b)
- ▶ Clinical assessment and differential diagnosis
- ▶ Functional assessment
- ▶ Combination of a selection of interventions for treating lymphoedema, including skin care, exercise, compression garments/bandages and lymphatic drainage (Lymphoedema Framework, 2006; Poage et al, 2008).

Lymphoedema treatment may be active or palliative. For example, patients with advanced and active disease may be treated with the agreement of their consultant. Palliative management is dependent on the individual's presenting symptoms, any concurrent medical treatment they are receiving and patient choice. Lymphoedema interventions are modified according to the patient's changing needs, and treatment is implemented all the while patients continue to experience positive results. Response to treatment is monitored using a comprehensive assessment tool, and evaluated over time (Lymphoedema Framework, 2006). The assessment tool used has been developed by lymphoedema specialists working with this group of patients in the London based clinic, and includes medical, physical and psychosocial history with diagrams and questions specific to patients treated for head and neck cancer:

**Monitoring pain and reduced range of function and movement**

Although surgical techniques have improved, surgery and radiotherapy can lead to the formation of scar tissue and anatomical changes which cause pain and deformity, which can also affect function and movement (van Wilgen et al, 2004). Monitoring pain is an essential part of assessment and a visual analogue scale (VAS) is used to measure pain intensity. For example, three patients seen in the author's lymphoedema clinic reported changes in their pain associated with mastication, all were referred back to the consultant surgeon. Two patients were diagnosed with radiation-induced osteonecrosis, and required surgical intervention to treat this problem, the third patient was diagnosed with recurrence of disease and discontinued lymphoedema treatment.

Any functional limitations, with an associated impact on lymphoedema treatment and outcomes, are recorded to provide a base-line against which to assess deterioration or improvement. For example, even if the accessory nerve is spared, traction on the nerve during surgery may result in damage (Buckley, 2000). Problems may not manifest until three to six months

**Table 1**

**Example members of the MDT (NICE, 2004)**

- |   |   |
|---|---|
| <b>Consultant surgeons:</b>   | » Restorative dentist                     |
| » Otolaryngologists, maxillofacial, plastic and reconstructive, endocrine, neurosurgeons, general surgeons with a specialist interest | » Physiotherapist                         |
| » Dietician   | » Occupational therapist                  |
| » Consultant radiologist  | » Head and neck clinical nurse specialist |
| » Consultant clinical oncologist  | » Community nurse                         |
| » Consultant medical oncologist   | » Lymphoedema specialist                  |
| » Speech therapist  | » Pathologist                             |
|   | » Ward nurse                              |
|   | » Secretary                               |
|   | » Palliative consultant                   |

following surgery, when the patient starts to present with limited range of shoulder and arm movement. Two patients who were identified with this problem acknowledged that they had not informed any other healthcare professional of difficulties with their mobility, both were referred to the head and neck specialist physiotherapist.

Trismus, difficulty in opening the mouth, can develop as a consequence of surgery and radiotherapy, or tumour infiltration (Feber, 2000c). This can lead to problems with eating and drinking, make oral hygiene difficult, and speech and social interaction can also be affected. Trismus can prevent accurate assessment of intra-oral swelling, and negate the opportunity to carry out intra-oral lymph drainage. In addition, it can limit the patient's ability to carry out specific exercises where muscle movement can help to stimulate lymph flow (Marieb, 1992). Where patients developed increasing problems with trismus while undergoing treatment for lymphoedema, they were referred back to the consultant surgeon to exclude the need for further investigations, and/or to access other lines of management.

**Nutritional status**

Surgery, chemotherapy and radiotherapy can all have effects on the tissues of the oral cavity, preventing or limiting oral intake (Russo et al, 2008). While patients

are unable to eat and drink normally, the insertion of a percutaneous endoscopic gastrostomy tube (PEG) for parenteral feeding aims to limit nutritional deficiency (van de Molen et al, 2009). However, patients may still develop absorption problems, and/or fail to ingest the amount of calories recommended. This can result in low serum albumin levels which may exacerbate facial swelling, limiting successful outcome of lymphoedema treatment. Patients receiving parenteral nutrition should be closely monitored by the dietician.

In the author's experience, checking the PEG insertion site at follow-up appointments is recommended, as two patients in the author's clinic have been identified with a local infection. One patient was successfully treated with oral antibiotics, the other patient required admission and temporary removal of the tube.

**Fatigue**

If radiotherapy includes treatment over the area of the thyroid, it can affect the normal functioning of the thyroid gland. Where patients have completed cancer treatment but report ongoing fatigue, hypothyroidism should be excluded (Tell et al, 2004).

**Skin and oral hygiene**

Radiotherapy affects the sebaceous glands, reducing the production of

sebum that helps to protect the skin (Edwards, 2000). This makes skin care and moisturising particularly important, as the head and neck are more exposed to the elements that can cause damage to the skin, thus increasing the risk of cellulitis and potentially triggering or exacerbating lymphoedema.

Salivary glands are sensitive to radiotherapy damage, and generally do not recover, resulting in reduced production of saliva (Someya et al, 2003). Saliva acts as a lubricant and has antibacterial enzymes and its absence can be one of the causes of a sore or dry mouth — xerostomia (Someya et al, 2003). Oral inspection routinely forms part of the patient's assessment, observing for signs of intra-oral oedema, and to ensure prompt onward referral should there be evidence of oral infections and/or candidias. The latter, if left untreated, can spread to the alimentary tract.

Good skin care and oral hygiene, including regular dental check-ups, are essential for this group of patients to minimise the risk of cellulites and dental caries. It is the policy at the author's clinic to provide all patients with information about the signs and symptoms of cellulitis associated with lymphoedema, and actions to take in the event of developing this condition.

Patients are advised to:

- ▶ Use a soap substitute, pat the skin dry and use a non-perfumed emollient two or three times a day
- ▶ Following radiotherapy, check that wearing cosmetics does not irritate the skin
- ▶ Wear a hat in the summer and apply sunscreen for skin protection
- ▶ Use an electric razor to reduce the risk of trauma to the skin
- ▶ Before using a depilatory cream, patch test elsewhere on the body to ensure there is no skin reaction
- ▶ Avoid electrolysis and waxing as both techniques increase the potential for bacteria entry, increasing the risk of cellulitis
- ▶ Xerostomia (dry mouth), sip water frequently during the day; may benefit from using a synthetic saliva
- ▶ Follow oral hygiene routine

as advised by medical, surgical consultant or speech therapist

- ▶ Avoid spicy foods, alcohol and tobacco, as these can make the oral mucosa sore, cause pain and discomfort even when cancer treatment has finished.

### External compression

The author acknowledges there is a lack of research based-evidence in the role of compression garments in the management of head and neck lymphoedema. The rationale for using compression garments in this group of patients in the London based clinic, is supported by existing evidence on the effects of compression on the underlying anatomy and associated physiological changes (Carati et al, 2009; Johansson 2009). In the author's experience, care needs to be taken with the selection of garment to reduce the risk of exacerbating swelling in other regions of the head and neck. In addition, compression needs to be applied with caution, to ensure that pressure applied over irradiated skin does not cause trauma or necrosis (Piso et al, 2001).

In the author's experience, selection of a compression garment is dependent upon the extent and stability of swelling, density of the tissues affected, and patient choice. Where swelling is confined to the submental region, an off-the-shelf garment such as a chin-strap may be enough. However, patients with more extensive swelling may require a made-to-measure garment.

Piso et al (2001) recommend that compression garments be worn for a period of four weeks, including overnight, with best results being achieved when this is combined with a course of manual lymphatic drainage (MLD). Although Piso et al (2001) suggest treatment should be carried out over a six-week period, the optimum length of time to treat patients using this method is not known.

In the author's experience, patients with head and neck cancer have reported that their swelling is worse first thing in the morning, even if they sleep with their head and neck well supported

and elevated. This pattern differs from other types of lymphoedema which are generally worse at the end of the day. Patient anecdotes suggest that where patients tolerated wearing compression garments overnight, they found their swelling was better controlled. Patients fitted with compression garments acknowledged that they did not wear these outside the home, as they were concerned that this would draw more attention to themselves.

Feber (2000d) reports that in some cases, patients have developed post-traumatic stress disorder associated with wearing a tight-fitting radiotherapy mask. A full facial compression garment can be a reminder of the mask worn during radiotherapy. Therefore, a sensitive approach needs to be taken to help identify which patients may be at risk of increased anxiety, or other psychological disturbances as a consequence of being fitted with this type of garment.

The use of textured pads may help to soften fibrosis (Strossenretuther, 2003a). Patients can wear textured pads under a scarf or compression garment; pads can also be inserted into made-to-measure garments or under bandages. The optimum level of time that pads should be worn is not known, but initially, patients are advised to wear them for one to two hours a day. If tolerated well, and benefits such as reduced swelling and/or softening of the tissues are observed, the length of time pads are worn can be increased.

A mouldable neck support was recently introduced at the author's clinic to help patients self-manage anterior neck and submental swelling. It is too early to say how effective this may be, however, patient feedback so far has been positive.

The application of compression bandages has recently been incorporated into treatment programmes, as described by Zanichelli and Gilbert (2009). In the author's experience, patients with a partner who can help to apply bandages have had a better outcome, although this will need to be monitored and evaluated over time.

**Manual lymphatic drainage (MLD)**

Priesler et al (1998), cited in the Clinical Resource Efficiency Support Team (CREST) Lymphoedema Guidelines (2008), conducted a retrospective study, and concluded that MLD therapy did not increase the risk of local recurrence of disease in patients treated for head and neck cancer with secondary lymphoedema.

As recommended in the CREST, document (2008), contraindications and relative contraindications are identified before starting MLD treatment (Table 2). Where limited evidence exists, these criteria are based on our understanding of the underlying pathophysiology.

Where the patient is known to have atherosclerosis, or considered to be at high risk, any neck treatment working over the carotid arteries is avoided to reduce the risk of causing micro-emboli that could cause transient ischaemic attacks (Strossenreuther, 2003b).

In the London based clinic, patients are seen on an outpatient basis. If the lymphoedema nurse recommends MLD as part of treatment, this is not started until three months post surgery and/ or radiotherapy. This is in line with local medical advice, and to allow for healing and for any post-inflammatory response to abate.

Where the patient cannot implement a self-care programme (Table 3) to manage their lymphoedema between clinic appointments, or self-management fails to reduce swelling, improve shape, soften fibrosed tissues and reduce discomfort or difficulties with swallowing, patients are booked in for a course of treatment, including MLD. Generally, this is a minimum of daily, 45-minute treatment sessions for two weeks.

The optimum number of MLD sessions or treatment period is not known. However, Thoma (2003) suggests that MLD may need to be carried out at least three to five times a day in some cases, but does not indicate length of treatment sessions or duration of course of treatment. In a study reported by Piso et al (2001), MLD was started between

**Table 2**

**Contraindications and relative contraindications of MLD**

Contraindications	Relative contraindications
<ul style="list-style-type: none"> <li>» Cellulitis</li> <li>» Uncontrolled heart failure</li> <li>» Acute renal failure</li> </ul>	<ul style="list-style-type: none"> <li>» Adherence of skin tissues to underlying structures following radiotherapy</li> <li>» Active disease</li> <li>» Unexplained pain</li> <li>» Avoid treating the neck if history of transient ischaemic attacks (TIAs)</li> <li>» Less than three months following surgery or radiotherapy</li> <li>» Inflammation of oral mucosa</li> </ul>

10 and 30 days postoperatively for two weeks, with sessions lasting between 30 and 60 minutes.

MLD, including intra-oral drainage, helps to reduce head and neck swelling and plays a key role in the management of this group of patients (Thoma, 2003). Additional benefits of MLD have been reported by patients. One patient stated, 'I no longer feel like I have a brick in my throat blocking my airway'. Other reported benefits include improvement in range of movement, enhanced self-esteem as physical appearance improved, and reduced pain. A speech therapist reported to the author that in her opinion, there appeared to be some correlation between patients having MLD and reduced swelling of internal structures, although this link has not been proven.

'Mapping out' MLD routines illustrates the sequence of treatment, which can help to facilitate shared care within the team. Kurz (1996) recommends working along the length of incisional scar tissue rather than working across the scar; but this is often not possible in this group of patients.

**Simple lymphatic drainage (SLD)**

In the early stages, patients are encouraged to carry out SLD (a modified form of MLD), at least once a day, not only to enhance benefits of other forms of lymphoedema treatment, but to help accurate recall of the routine and

technique. In the author's experience, in four cases where the patient and their carer were taught SLD and they carried this out as advised, the patient did not need to proceed to a course of intensive treatment with MLD. Patients were provided with diagrams and written instructions to follow. Visual instructions on DVD are available in the USA, but to the author's knowledge none have been produced in the UK for head and neck lymphoedema.

Over time, the frequency with which SLD is carried out is reduced to fit in with the patient's lifestyle and to achieve

**Table 3**

**Self-management techniques**

- » Skin care
- » Exercise
- » Deep breathing exercises
- » Simple lymphatic drainage
- » Kinesiology taping
- » Textured lymph pad
- » Mouldable neck support
- » Compression garment
- » Bandaging

control/maintenance of lymphoedema. Attendance at follow-up appointments for review of the patient's progress includes assessment of their SLD technique, so it can be refined, adjusted or corrected as necessary.

### Exercise

The effects of MLD and SLD can be enhanced by patients carrying out exercises with muscle pump action stimulating lymph flow (Casley-Smith and Casley-Smith, 1997; Moseley and Piller, 2008). Research-based evidence supporting the effectiveness of specific exercises in this group of patients is not available. The author's rationale for recommending that the distal muscles be exercised first follows the principles of MLD, that is, to enhance the effect of the muscle pump to empty lymph from distal regions working back towards the affected area. The Lymphoedema Support Network (LSN) leaflet on Head and Neck Lymphoedema also outlines an exercise routine that broadly follows this principle (Lymphoedema Support Network, 2005).

Moseley et al (2005) conducted work with breast cancer patients and their findings suggested that deep breathing helped to increase lymph flow/return of lymph to the blood circulation. While research on the effectiveness of deep breathing on lymphoedema for patients with head and neck swelling has not been published, patients are taught this technique because of its potential benefits.

Where patients have had a hemiglossectomy, or other treatment that affects their swallow reflex, and they are at high risk of aspiration because of their inability to protect their airway, they are not encouraged to chew sugar-free gum as part of an exercise routine. However, patients are taught exercises that work the muscles of the face, to help stimulate lymph flow.

### Additional treatments

#### Low level laser therapy

Papers accessed by the author predominantly discussed treatment of breast cancer related lymphoedema using low level laser therapy (LLLT) (Thelander, 1994; Carati et al, 2003; Laakso, 2006; Kozanoglu et al, 2009; Tilley, 2009).

Tilley (2009) highlights that a number of theories have been put forward about the effects of LLLT on the tissues, including its stimulatory effect on the growth of new lymph vessels, which in turn enhances lymph flow. Additional effects include softening of scar and fibrosed tissues, reduction in swelling and reduced pain in the affected area. Given these benefits, LLLT has potentially exciting possibilities for treating patients with secondary head and neck lymphoedema in the future.

While acknowledging further research in this field is necessary, Wigg (2009) found that LLLT was an effective part of treatment for three patients who developed lymphoedema secondary to head and neck cancer.

Tilley (2009) reports that consensus in the use of LLLT, including the optimum frequency and dosage to produce the best outcomes for patients has not yet been agreed upon in Australia. However, The Australian Lymphology Association (ALA) has adopted common protocols while awaiting outcomes of further research in the use of LLLT.

#### Kinesiology taping

There is limited research-based evidence to support the use of kinesiology tape in the treatment of head and neck lymphoedema, however, it has been used widely in the management of sports injuries (Finnerty et al, 2010). Kase and Stockheimer (2006) suggest that the elastic properties of the kinesiology tape, when applied correctly, can help to direct lymph flow away from a congested area, and a study conducted by Bosman and Piller (2010) demonstrated that kinesiology taping can have beneficial effects in reducing 'extracellular fluid accumulation'.

In patients whose skin is healthy and intact, kinesiology tape is applied after 'patch testing' to exclude an allergic reaction. Tape is used with caution and is not applied close to or over areas of irradiated skin, due to the increased risk of trauma and skin sensitivities developing.

Where kinesiology tape produces positive results for the patient, i.e.

reduced swelling and/or softening of the tissues, the tape may continue to be used within their maintenance programme, with assessments at regular intervals to monitor their progress. Patients are taught how to safely apply and remove the tape, and they are provided with written guidelines.

#### Deep oscillation therapy

Jahr et al (2008) reported that deep oscillation therapy, as a supplement to MLD, reduced pain and swelling in patients with breast cancer-related lymphoedema. At the present time, the benefits of this form of therapy for patients with head and neck lymphoedema secondary to cancer is not known.

#### Psychosocial impact

Patients referred to the London based lymphoedema service have reported a range of physical and emotional challenges associated with their cancer treatment, including increased levels of anxiety and depression. Patients also reported that lymphoedema increased their fear of recurrence of disease, even when this had been excluded.

As well as trying to cope with an altered body image, patients have reported feeling overwhelmed and exhausted by their cancer journey, including attendance at numerous appointments with other members of the MDT. To alleviate the burden of even more appointments, the aim of the lymphoedema specialist has been to introduce methods of self-management from the outset, and patients are encouraged to bring their partner/main carer with them.

Data for Head and Neck Oncology (DAHNO, 2010) cite that where socio-economic deprivation exists, patients do less well than their affluent counterparts. Where economic/financial factors affect access to the lymphoedema service, patients, if they wish, can be referred for financial advice/support, for example, they may be entitled to reimbursement of travel costs.

NICE (2004) identified that where patients have a dependence on alcohol

and/or tobacco, they may need assistance to maintain long-term abstinence. Within the clinic, patients are observed for signs of withdrawal symptoms and/or behaviour changes, so that timely access to specialist support can be arranged within their rehabilitation programme.

### Measuring outcomes

Improved data collection will be essential for the whole of the patients pathway, in order to better understand the impact of different aspects of treatment on outcomes for patients (van der Molen et al, 2009; DAHNO, 2010). Measuring and understanding outcomes will be key to ensuring that patients receive the right treatment at the right time if their quality of life is to improve. In the author's opinion, this reinforces the need to develop and use specific validated assessment tools for patients with head and neck lymphoedema, the aim being to collect accurate and consistent data that can be evaluated over time. It is anticipated that this would help to identify which lymphoedema interventions are most effective at different stages within the patients' treatment programme.

Photographic evidence has been used to 'measure' swelling and to evaluate response to treatment over time in the London clinic. The feasibility of using other methods to measure outcomes are being explored, including 3-dimensional (3D) imaging. Papers by Kau et al (2007) and Paviotti et al (2009), report on techniques to measure face morphology, including the development of 3D imaging devices, for example, hand-held scanners used with digital cameras. In the author's opinion, further investigation is required to identify the benefits, limitations and cost-effectiveness of introducing 3D measuring techniques, and whether the images produced can be used to analyse lymphoedema in the head and neck, including the patient's response to lymphoedema management over time.

Other manual techniques to measure head, facial and neck swelling are still being explored by the author, as identifying exact landmarks on the face and neck as reference points for measuring is complicated and affects accuracy and reproducibility over time (Piso et al, 2001).

The patient's perception and description can provide a source of useful information. However, it is acknowledged that an element of bias cannot be excluded, particularly if the patient is relating information back to the specialist treating them. One proposal to better understand the impact of lymphoedema and its management on this group of patients is to conduct one-to-one interviews with a healthcare professional who is not linked to the service. It is too early to say whether this would lead to a quality of life assessment tool specific for this group of patients.

Diagrams of the head and neck are also useful for recording areas of swelling, areas of scar tissue and which areas are affected by pitting oedema or fibrosis, and evaluating changes over time.

Where patients need to have fluoroscopy to assess swallow reflex (van der Molen et al, 2009), it may be possible to assess if lymphoedema treatment has produced any physiological changes. This technique would only be performed if appropriate within the patient's cancer treatment programme to avoid exposure to additional unnecessary doses of radiotherapy. Ethically, fluoroscopy could not be used as a routine method for assessing reduction in swelling of internal structures.

### Conclusion

While lymphoedema may not present as an emergency crisis for patients treated for head and neck cancers, accessing timely treatment can still have a profound beneficial effect on patients' physical and psychosocial wellbeing.

To understand what constitutes 'best practice' in the management of secondary lymphoedema in this group of patients, and to provide recommendations about the most effective and optimal way to treat and support patients and their carers, it is essential that further evidence-based research is conducted.

Accurate measurement of outcomes relating to specific head and neck lymphoedema interventions will be key to ensuring that patients receive the right treatment, at the right time,

to help improve their quality of life. Lymphoedema specialists working with patients and members of the MDT are ideally placed to address these challenges. JL

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