

The delivery of lymphoedema care to patients in the end stages of life: key factors and their potential to influence practice

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Key words

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End of life care includes palliative care for people likely to die within a period of 12 months (NHS, 2018). This includes patients whose death is imminent and those with advanced, incurable conditions (The Choice in End of Life Care Programme Board, 2015). Lymphoedema is a chronic form of swelling (oedema) due to the accumulation of fluid in the subcutaneous tissue layer of the skin. The oedema can be mild or severe and affect one or more limbs, the head and neck, and all anatomical parts of the body trunk. Lymphoedema is a common feature of many chronic conditions in the latter stages of life (International Lymphoedema Framework [ILF], 2010; *Table 1*). Although not fatal, the sequelae affects peoples' quality of life in the terminal stages of disease (Hewitt et al, 2010). For example, pain, heaviness, lymphorrhoea (*Figure 1*) (leaking lymph fluid), cellulitis (infection) (*Figure 2*) and reduced function and mobility of the swollen anatomical part.

In line with the World Health Organization (2019), the principles of care for patients with end of life oedema include

Abstract

Underpinned by her experience as a lymphoedema clinical nurse specialist, the author provides an overview of the key factors and their influence on the delivery of quality lymphoedema care to patients in the end stages of life. The account is described from the perspective of the lymphoedema practitioner, the delivery model of National Health Service (NHS) lymphoedema service provision in the UK and the service specification. The objective of the article is to raise an awareness of the significance of the factors to lymphoedema practitioners and NHS commissioners of lymphoedema services for consideration as part of the tendering process.

Table 1. Causes and pathophysiological consequence of oedema in the terminal stages of life (International Lymphoedema Framework, 2010).

Oedema causes	Pathophysiology
Advanced cancer	Metastatic lymphadenopathy, previous surgery, radiotherapy, tissue infiltration, venous thrombosis
Chronic heart failure	Venous hypertension (fluid overload), ascites, anaemia
Neurological disease	Extrinsic muscle loss / immobility (cerebral vascular accident, motor neurone disease)
Liver disease	Hypoalbuminaemia (proteinuria)
End stage renal disease	Venous hypertension (fluid overload), Hypoalbuminaemia
End stage respiratory disease	Heart failure (cor pulmonale), Hypoalbuminaemia
Medications	Corticosteroids, cytotoxic chemotherapy, calcium antagonists, bisphosphonates, anticonvulsants

the relief of symptoms, an improvement in quality of life and a reduction in risks associated with the oedema, e.g. cellulitis and lymphorrhoea (ILF, 2010). Patients with advanced disease may not be able to tolerate a full programme of assessment and lymphoedema treatment, e.g. multi-layer bandaging, robust compression garments and exercise. Instead a palliative approach is required in which lymphoedema treatment

is modified and selected to ease specific symptoms, e.g. low-level compression garments, kinesio taping and manual lymphatic drainage (MLD) (ILF, 2006).

Reflecting on her experience, the author will provide an overview of the issues and their influence on good quality lymphoedema care in the end stages of life. The patient will remain at the centre of this article. The number of influences described is considered

not to be exhaustive and is reported from the perspective of the lymphoedema practitioner, the delivery model of the NHS lymphoedema service and the service specification. The overlap of the influences between the different perspectives should be noted.

The patient

The care of terminally ill patients involves a personalised integrated, joined-up approach to enable them to live well and die well (Thomas and Armstrong-Wilson, 2016). Crucial to the ethos is enabling patients to make health and lifestyle choices (Figure 3).

The capacity of patients with lymphoedema to make health and lifestyle choices in the terminal stages of life is influenced by their physical, social, psychological and spiritual wellbeing (ILF, 2010). Poorly controlled symptoms can lead to considerable distress (National Institute for Health and Care Excellence [NICE], 2015). However, a patient's acceptance of lymphoedema care will be decided by them, in consideration of their family, (Lymphoedema Framework, 2010), their tolerability to treatment (Hewitt et al, 2010) and in relation to the diversity of characteristics of their terminal disease:

- Disease prognosis (newly diagnosed or the final days of life)
- Physical function (walking, weight bearing or bedbound)
- Lymphoedema symptoms (mild or severe swelling, cellulitis, lymphorrhoea, ascites, chylous reflux)
- Other symptoms (breathlessness, pulmonary embolus, deep vein thrombosis, fungating wounds)
- Adjuvant treatments (radiotherapy, chemotherapy)
- Treatment consent (advanced treatment directives, power of attorney, unconsciousness).

A patients' response to the need for treatment and its type can be diverse. Some patients are in denial of their terminal prognosis and non-accepting of any form of lymphoedema treatment, regardless of the extent and severity of symptoms. Other patients physically struggle with the impact of lymphoedema care and become fatigued from the burden of multiple appointments for treatment to control symptoms such as lymphorrhoea (leaking lymph). Still other patients embrace treatment in anticipation that symptom control will enhance their function to enable outings and holidays with their family. Finally,



Figure 1: Skin excoriation with lymphorrhoea.



Figure 2: Cellulitis in a lymphoedematous arm.



Figure 3: What is important to me? Taken from: *The Care Review: A Review of Choice in End of Life Care* (2015).

there are patients in the final days of life who become reliant on healthcare professionals and family treating in their best interest because of an unresponsive, unrousable state (coma).

Treatment strategies for lymphoedema in terminally ill patients relies upon the modification of the core treatments (ILF 2006), e.g. the application of cotton retention bandages, as opposed to short stretch to contain/resolve lymphorrhoea (Palliative Care Adult Network Guidelines, 2016) and lower grades of hosiery to support swollen, sensitive tissue when firmer compression cannot be tolerated (Butterfield, 2013).

Paradoxically, the physical and psychosocial effect of treatment can increase patient distress and influence their choice and acceptance. Applications of kinesiology

tape and head and neck garments can draw attention to facial oedema. The need for prescription footwear for swollen feet and palliative bandaging of lower limbs to resolve lymphorrhoea can undermine independence (Hewitt et al, 2010) and increase the risk of falls. Treatment to reduce genitalia oedema and aid micturition can be unmanageable for male patients because of the dexterity of hand and finger movement needed to apply small retention bandages.

The lymphoedema practitioner

The needs of patients with lymphoedema who are otherwise ill with advanced disease can, therefore, be complex (Lymphoedema Framework, 2006) and challenging for a lymphoedema practitioner to manage (International Lymphoedema Framework,

2010). The key causes of the oedema can further compound the choice of treatment because the swelling is rarely due to lymphoedema alone (Palliative Care Adult Network Guidelines, 2016; Table 1). Treatment instigation may be further influenced by the competence (qualifications and experience) of the lymphoedema practitioner.

A highly experienced lymphoedema practitioner is capable of autonomous practice in the treatment of complex oedema with systemic involvement; frequently advising medical teams surrounding treatment efficacy and the use of medications e.g. diuretics to remove fluid and antibiotic regimens to treat cellulitis. Whereas, a less experienced lymphoedema practitioner may need to seek clarification from the multidisciplinary team surrounding diagnosis and the safety aspect of treatment.

Lymphoedema care is further influenced by the clinical judgement and contextual sensitivity of lymphoedema practitioners to know when death is imminent, and treatment no longer appropriate. Alternatively, when life is more prolonged, and a more robust treatment approach relevant, one that also allows for an adjustment of treatment goals as life diminishes (Lymphoedema Framework, 2010).

Consistency in lymphoedema palliation also relies on the organisation and flexibility of the clinical lymphoedema workforce because the ways people die and how long this takes varies widely (NICE, 2015). Patients can die very quickly or spend weeks or months in a gradual or intermittent decline. Unplanned hospital or hospice admission for acute medical intervention or symptom control (respectively) can hinder access to treatment because of a sudden move in the patient's location. The size of the lymphoedema workforce and extent of the skill mix will determine the capacity for appointments that also accommodate oedema complications and deterioration due to disease progression.

The model of service delivery

Providing the right service at the right time, in the right place (The Choice in End of Life Care Programme Board, 2015) for terminally ill patients will be influenced by the operational components of the model of service delivery. NHS funded lymphoedema services operate from hospitals (acute), GP surgeries, healthcare centres (community)

Table 2. The influence of patient distress and the effect on their treatment choice. Comments made by patients at assessment appointments during 2018.

Patient comment	Oedema area & best practice	Patient choice
“No one told me this would happen, I feel so disfigured”	Facial oedema: offer of kinesio taping, head and neck garments	Decline of both treatments (MLD and instruction in SLD as an alternative)
“All I want to do is to be able to fit in to some shoes that I feel safe to go out in”	Gross pedal oedema, lower limb lymphorrhoea: x-large formulary shoes and palliative bandaging	Decline of footwear-risk of falls. Bandaging acceptance Remaining housebound
“If only I could pee properly. I don't want to end my days with a catheter”	Gross penile and scrotal oedema necessitating retention bandaging and scrotal support	Decline based on dignity “I'll manage without” (MLD and instruction in SLD as an alternative)

and hospices (British Lymphology Society, 2019). Lymphoedema services with no facility to undertake home or hospice visits put the onus on the patient to attend the clinic for treatment. This is not always possible for poorly patients experiencing a physical deterioration due to advancing disease. Alternatively, lymphoedema services commissioned to undertake home and hospice visits are better placed to provide a personalised integrated care approach because the model facilitates healthcare outcomes through collaborative working with the multidisciplinary team at the patient's location (Morley and Cashall, 2017). For example, joint home visits with community nursing teams for the treatment of fungating wounds in the presence of lymphoedema and the treatment of pedal oedema to enhance patient mobility in collaboration with the physiotherapy team.

The service specification

Care that is truly centred on terminally ill patients requires a skilled, capable and flexible workforce (The Choice in End of Life Care Programme Board, 2015). The standard of care expected of an NHS-funded lymphoedema service will be defined by the core standards in the service specification (NHS England, 2019). The 'particulars' of the service specification, determined by the local NHS commissioners, will include the size and skill mix of the workforce. This is influenced by:

- The allocated budget surrounding staff, direct and indirect costs (British Lymphology Society, 2019a).
- The workforce ratio guidance of 220–250 patients per full-time therapist with

supporting staff (Thomas and Morgan, 2017)

- The prevalence of lymphoedema within the CCG(s), (since 2019, can be calculated using the BLS Cost Calculator, 2019b)

Therefore, as a general rule, NHS funded lymphoedema services that are contracted to treat all types of lymphoedema (primary, secondary and end of life care) for multiple clinical commissioning groups (CCGs) are comprised of a large workforce. Alternatively, NHS-funded services contracted by one CCG to treat specific lymphoedema cohorts (cancer and end of life care) are likely to operate with a much smaller workforce. Sometimes with the service comprising of a single staff member with no cover in the event of sickness or annual leave.

Regardless of the variance in the size of the workforce, the effectiveness and sustainability of a service will also be significantly influenced by the experience of the lead lymphoedema practitioner. Assessment skills to obtain differential diagnosis and instigate competent treatment to patients will be dependent on their level of clinical expertise, service managerial skills and collaboration with multidisciplinary teams, e.g. oncologists and hospices.

The service specification will contain other 'particulars' relevant to the local health population and influencing patient treatment. For example:

- A dedicated budget for the purchase of compression products not available from the NHS on prescription, e.g. neck collars, scrotal and abdominal supports. An inadequate budget will impose a risk to the increase of oedema in patients because of non-availability. A small or

non-existent budget will risk an unmet clinical treatment need for terminally ill patients requiring support and control of midline oedema

- Clinical limitations with the provision of MLD. In respect of staff resource and maintaining appointment capacity, service specifications sometimes limit the provision of MLD to midline oedema only. Contractual limitations in the use of MLD can result in an unmet clinical need. Enabling a Lymphoedema Practitioner to undertake MLD at their clinical discretion to poorly patients with, for example, flail arms created by brachial plexus injury, can improve quality of life because of the

reduction in pain and discomfort

- An uncapped caseload can influence service sustainability and staff wellbeing. Open access to referral resulting in infinite caseloads that are not matched by staff recruitment of more lymphoedema practitioners is likely to dilute the quality of lymphoedema treatment due to overstretched resources.

Conclusion

Treatment of lymphoedema in the end stages of life is challenging because of the complexity of the disease process and mixed aetiology of the oedema. This article has highlighted key factors with the potential to further impact on

the complexity of lymphoedema care in the end stages of life from the perspective of the lymphoedema practitioner, the service model of delivery and the particulars of the service specification.

It is hoped that this overview of the key factors will be of benefit to healthcare professionals, lymphoedema practitioners and NHS commissioners of lymphoedema services for consideration of their provision for terminally ill patients with chronic forms of swelling. In doing so, also optimising lymphoedema healthcare outcome(s), enabling individuals with lymphoedema to live comfortably through their end stages of life.

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