The prevalence and treatment of oedema at the end of life: a retrospective review of 400 cases

Angela Huor and Amanda Landers

Angela Huor is Trainee Intern, Department of Medicine, University of Otago, Christchurch, New Zealand; Amanda Landers is Palliative Care Physician, Senior Clinical Lecturer, Department of Medicine, University of Otago, Christchurch, New Zealand.

Acknowledgements: The authors gratefully thank Nurse Maude Hospice Palliative Care service for supporting the study.

Conflict of interest: None of the authors have any competing interests.

Funding; This work was supported by the Oncology Trust Fund, Canterbury District Health Board, New Zealand.

Abstract

Oedema at the end of life (OATEOL) is common and causes functional disability and psychological distress. The purpose of this study was to estimate the prevalence of OATEOL in a palliative care population and document the treatment options being offered. A retrospective case note review of 400 patients was conducted by the authors. Of the patients reviewed, 114 (28.5%) had a diagnosis of OATEOL. Most patients had a primary diagnosis of malignancy (78%) and approximately a quarter had non-cancer illnesses (22%). OATEOL was categorised as either lymphatic, non-lymphatic or mixed oedema. The majority of participants with OATEOL were categorised as non-lymphatic. Across all oedema subtypes, the range of treatments offered were inadequate and inconsistent according to best practice.

Peripheral oedema is a common clinical sign of many pathologies. Oedema at the end of life (OATEOL) is a term used by the International Lymphoedema Framework (ILF, 2010) to describe types of chronic oedema that develop in severe, advanced illness. Chronic oedema is generally defined as swelling that has been present for 3 months or more (Keast, 2015) Common causes of OATEOL include advanced cancer complications (Abu-Rustum et al, 2006; Ohba et al, 2011; Beesley et al, 2015), advanced organ failure (heart, liver, kidney, respiratory), hypoalbuminaemia, venous hypertension and immobility (Sitzia et al, 1998).

OATEOL is likely due to a combination of these factors. It may be further classified as lymphoedema or non-lymphatic oedema or a combination of both (Caban, 2002; Real et al, 2016). Lymphoedema is caused by lymphatic dysfunction, most commonly secondary to surgery or radiation treatment, or by direct obstruction by tumour or lymph nodes.

The prevalence of OATEOL in a specialist palliative population has been reported to be between 5 and 51% (Potter et al, 2003; Teunissen et al, 2007; Real et al, 2016; Best et al, 2018) depending on the setting, definition and underlying diagnosis. OATEOL is, therefore, common and causes symptoms such as pain and heaviness, which have clinically significant impacts on patient mobility (Landers and Holyoake, 2019), function, self-image, relationships and general quality of life (Fu et al, 2013). It also carries a significant risk of infections, such as cellulitis, erysipelas and lymphangitis. Lymphorrhoea is another complication of oedema, which is where potentially large volumes of fluid leak from the interstitial space through the skin. This can be due to both lymphatic (malignancy) and non-lymphatic (e.g. heart failure) causes.

Patients with OATEOL should receive coordinated services and information appropriate to their requirements. There are effective oedema management strategies that are now being recommended in patients with OATEOL (ILF, 2010; Cheville et al, 2014), although robust evidence of benefit is still lacking (Leung et al, 2015). A question remains about the different treatments that should be offered depending on the type of oedema. Treatments specific to lymphoedema include manual lymphatic drainage (MLD) (Clemens et al, 2010), complex decongestant therapy (which comprises of skin care, exercise, compression bandaging and MLD) (Cobbe et al, 2018), assistive devices and kinesiotaping. Non-lymphatic oedema may benefit from diuretics, fluid restriction and local resorption of the fluid using compression garments. Measures such as subcutaneous needle drainage (Clein and Pugachev, 2004; Landers and Holyoake, 2019), skin care and exercise may help all types of OATEOL. Many of these therapies have basic approaches that can either be performed by clinicians, or taught to patients and families to promote self-management in the community. These therapies must be tailored to individual goals and the aim is to improve quality of life (Cooper, 2012). Due to the lack of current research in this area, however, it is difficult to know what treatments are being offered routinely to palliative patients with OATEOL.

The New Zealand health system is

largely publicly funded by the government. Accessible and affordable lymphoedema services for patients at the end of life in New Zealand is sporadic. The concept of OATEOL itself is not yet well-known or utilised, and the prevalence of OATEOL and the treatments offered in New Zealand is currently unknown. Hospice services may offer expertise in their region, but this is not uniform throughout the country (New Zealand Lymphoedema Therapists, 2010). With many services vying for scarce health dollars, lymphoedema can be low priority despite its significant effect on patients at the end of life.

AIM

The aim of this study was to assess the prevalence of OATEOL in a large specialist palliative care population in Canterbury, New Zealand, and identify the treatments that have been offered to patients. This information will identify unmet needs in the health service in order to inform future practice.

Method

A retrospective case note review was undertaken for deceased patients referred to the Nurse Maude Hospice Palliative Care service between January 1 2018 and December 1 2018. Case notes were screened alphabetically by patient name until 400 patients had been reviewed in total. An initial pilot was performed using 50 patient files in order to refine the audit tool and optimise data collection.

Case notes were screened for 'oedema' in the clinical documents, such as palliative care assessments, clinic letters, discharge summaries and referrals. Any patient that had 'oedema' in these documents was included in the analysis. Patients were excluded if the cause of oedema was acute and could be resolved, such as acute heart failure and deep vein thrombosis.

Data on the following were collected and entered onto the audit tool:

- Demographics
- Primary diagnosis
- Referral information
- Presence of oedema.

If 'oedema' was present, patients' clinical progress notes were then reviewed by the two authors (AH and AL) to determine the cause of oedema, types of oedema and treatments offered to manage the problem. Cause of oedema was determined by a combination of clinical judgement by authors and medical examination, assisted by laboratory tests where recorded. Treatments offered were categorised in the audit tool according to best practice guidelines. Microsoft Excel (Microsoft, Redmond, WA) was used for statistical analysis of the data. This low-risk study was not deemed to require national Health and Disability Ethics, but was instead reviewed and approved by the Nurse Maude Hospice Palliative Care Ethics Committee.

Table 1. Participant demographics and causes of OATEOL (*n*=114).

Demographic/comorbidity	
Age, median (range) years	70.7 (36–96)
Female, *n*(%)	54 (47)
Comorbidities	
Malignant, *n*(%)	89 (78)
Breast	13 (15)
Colorectal	11(12)
Other GI	23 (26)
Haematological	9 (10)
Lung	8 (9)
Prostate	7 (8)
Skin	5 (6)
Gynaecologicalm	2 (2)
Unknown primary	2 (2)
Other	9 (10)
Non-malignant, *n*(%)	25 (22)
Heart failure	16 (64)
Renal failure	3 (12)
Chronic lung disease	2 (12)
Neurodegenerative	2 (8)
Liver failure	1 (4)

Table 1. Participant demographics and causes of OATEOL (*n*=114).

Classification of oedema	**n(%)**
Lymphatic	4 (4)
Non-lymphatic	86 (75)
Mixed	18 (16)
Unknown	6 (5)
Lymphorrhoea	15 (13)

Results

Demographics: The majority of referrals to specialist palliative care during the time period came from local tertiary hospitals (64.5%) and primary care (23.5%). Out of 400 patients reviewed, 114 (28.5%) had OATEOL. Most patients were referred with a primary malignancy (78%), while the remaining 25 patients (22%) were referred with non-cancer diagnoses [Table 1}.

Of those with cancer diagnoses, the most common types were breast (15%) and colorectal (12%) cancers. Heart failure was the most common non-cancer diagnosis (64%), followed by renal failure (12%) and chronic lung disease (12%).

Oedema: Eighty-six patients (75%) had non-lymphatic oedema, four patients (4%) had pure lymphoedema and 18 patients (16%) had mixed oedema [Table 2]. The mixed group had a clear combination of both types of oedema. For example, cases had low albumin (non-lymphatic) secondary to malignancy, but also a diagnosis of pelvic nodal involvement (lymphatic). In a few instances (six patients), it was difficult to ascertain whether the patients had lymphatic, non-lymphatic or mixed oedema. These patients had oedema mentioned in their notes, but there was insufficient information to deduce the type; these were classified as 'unknown'. Fifteen patients had lymphorrhoea in this review (13%). In total, 20% patients had a lymphatic component to their oedema and 91% had a non-lymphatic component.

Treatments: The data were analysed to identify the treatments that patients received to manage the chronic oedema [Figure 1]. Notably, patients could have received more than one option. Massage and compression bandaging were the most common treatment modalities offered or accessed by patients. Of the 104 patients with a non-lymphatic component, 37 patients received diuretics and five were on fluid restriction (four with heart failure and one with end-stage renal disease). Approximately one quarter of patients were advised to elevate or reposition oedematous areas, and only one case note mentioned exercise. Of the 22 patients with a lymphatic component, none were advised about exercise, fluid restrictions, or were referred to a specialist lymphoedema service. There were four cases of lymphoedema, involving either surgical removal of nodes or tumour infiltration. Two of these patients were

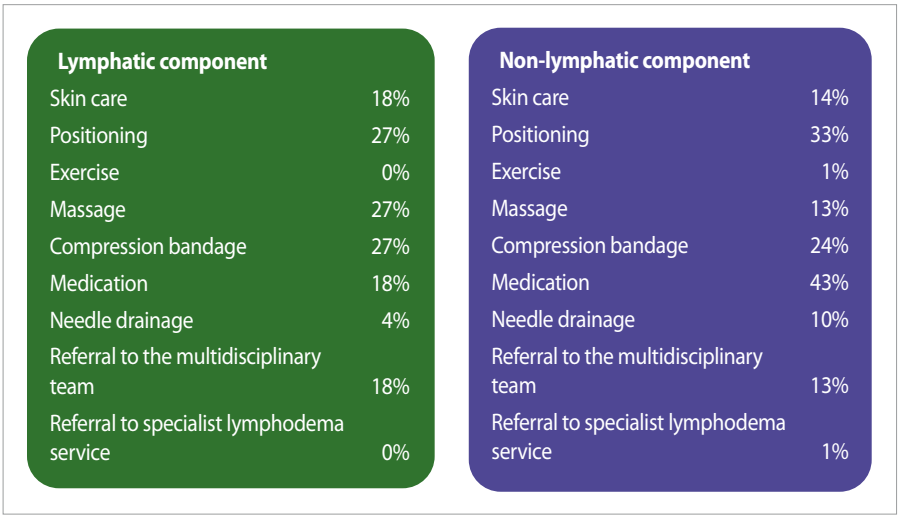

Figure 1. Frequency of treatments offered to patients with lymphatic or non-lymphatic components of odema at the end of life.

educated about positioning. Two had no treatment options recorded in their notes. Approximately 10% of the non-lymphatic cases were offered subcutaneous needle drainage.

Discussion

OATEOL describes peripheral swelling that occurs as illness progresses to an advanced stage. Almost 30% of all referrals to the specialist palliative care service had OATEOL. Most of these patients had malignancies, but over 20% were referred with a non-malignant disease. The vast majority had non-lymphatic oedema secondary to causes unrelated to a dysfunctional lymphatic system. Treatments offered mainly included diuretics, positioning and compression bandaging. Few people appeared to be given advice about skin care, exercise, massage, and even fewer were referred to a multidisciplinary team or specialist lymphoedema service.

The prevalence of OATEOL in patients referred to the specialist palliative care service was 28.5%, which is less than previous studies. Best (2018) reported a 50% prevalence of oedema in 59 hospice inpatients. Another study of 50 patients admitted to a palliative care unit described a 43% prevalence of peripheral swelling (White et al, 2009). The patient population in this study differs from previous research as it includes both inpatient and community-based patients. Potter et al (2003) reported a similar patient group referred to a palliative care service in London, England of 400 inpatients and outpatients. They investigated symptoms at the end of life and found a 12% prevalence of oedema. This was much lower than reported in the present study (28.5%); however, 95% of their patients had a cancer diagnosis compared to 78% in this study. Despite these different statistics, OATEOL is consistently shown to be a very common symptom in life-limited illness.

It is important to categorise the type of oedema if there is a potential change to management. In the non-palliative care population, intensive treatments such as complex decongestant therapy are utilized as a first-line treatment to prevent further deterioration. However, this is not realistic in patients with advanced and progressive disease where the primary treatment aim is to increase their quality of life.

Each patient in the present study was, therefore, categorised into lymphatic, non-lymphatic and mixed oedema. This was completed using the categories proposed by Real et al (2016) who found that almost 80% of their cases had a non-lymphatic component. This is similar to the findings here, however, they did report a higher percentage of patients with isolated lymphoedema. The authors' study had a much smaller number due to having a larger non-cancer population and we only classified patients with clearly dysfunctional lymphatics into this group. It is possible that at a biological level, general fluid congestion eventually overwhelms the lymphatics, and the majority of lymphatic and non-lymphatic oedema is actually of mixed aetiology as suggested in the literature (Real et al, 2016; Cobbe et al, 2017; Gradalski et al, 2019). The rates of lymphorrhoea were similar to previous publications (Real et al, 2016; Cobbe et al, 2017).

Standard treatment for lymphoedema can be extrapolated to all types of oedema, particularly as many of them are simple and effective. The patients in our study did not appear to get standard advice about skin care and positioning. Very few cases with a lymphatic component were taught or given education about massage. About one-third of patients with dysfunctional lymphatics accessed compression bandaging. The use of diuretics was reasonably common in the non-lymphatic group, as would be expected in chronic heart failure and cor pulmonale. For these patients, who have potential reversible causes for their oedema, simple interventions such as diuretics and fluid restrictions are part of standard therapy. These treatments would not be useful for patients with lymphoedema, and could cause more harm in cases of multi-organ failure and hypoalbuminaemia. Overall, there were very low rates of referral to a multidisciplinary team or a specialist service. Severity of oedema was not assessed in the authors' study as there was insufficient and inconsistent data to form a meaningful conclusion; however, informally the severity of oedema ranged from mild to very significant. Though mild cases could be sufficiently managed in the community, complex patients are likely to require specialist input, which is currently lacking.

The best practice management of all forms of OATEOL has a holistic and team approach. Successful management relies heavily on patients and carers playing a pivotal role in the care. This study has revealed that a substantial proportion of palliative care patients in a specialist service experience OATEOL. It is likely that the problem is underestimated in the wider community as this study excluded patients who did not utilise specialist palliative care services. The local publicly funded lymphoedema services are woefully inadequate. There is one under-resourced clinic based at the Older Person's Health Hospital, which is unable to provide service to palliative care patients. The other practitioners are all privately funded, which exacerbates inequities in the system. It also results in patients not being properly diagnosed or assessed, leading to the

incorrect assumption that the condition is rare, inconsequential to patients, is not potentially life-threatening and has few treatment options. Nurse Maude Hospice has on average 200 new referrals per month and over 2,000 referrals annually. Extrapolating the prevalence identified in this study, it is estimated that 570 patients with OATEOL will present to the service each year, where there no available lymphoedema expertise.

This retrospective case note review is the first of its kind in the New Zealand palliative care setting and offers valuable information on the prevalence of OATEOL in patients. It is difficult to generalise the results of this study as it was conducted in only one centre; however, a large number of patients' notes were reviewed. It is also a retrospective review, which has inherent limitations as it is based on what is recorded in the notes by clinicians. The main source of measurement bias is the subjective nature of the oedema diagnosis and the lack of objective information regarding treatment. 'Oedema' is a clinical diagnosis by nature. For a patient to be included in the study, the diagnosis of 'oedema' and its treatment had to be written in the clinical notes. These were mostly handwritten and could have been misinterpreted by the researcher reviewing these notes. This is likely to have underestimated the actual education being conducted and the treatments that were offered. This would suggest that more standardised measures of reporting assessments and treatments are required to ensure quality care for patients with OATEOL.

Conclusions

This study demonstrates that a high prevalence of patients at the end of life have oedema. It also highlights the difficulties with systematic assessment and treatment offered to these patients. The term OATEOL is one that may present some clinical utility. Diagnosing a palliative patient with OATEOL is the first step to recognising the importance of assessment and the correct treatment pathway. After diagnosing OATEOL, the next important question is whether the oedema has a lymphatic, non-lymphatic or mixed aetiology. This then allows the clinician to tailor the treatments offered for the best outcomes by stratifying patients into different severity groups. Those with simple or mild OATEOL can be given education and advice about skin care, positioning, exercise and massage, while those with complex needs may require a specialist referral.

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