

Lower-limb oedema at the end of life: how common is it?

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Key words

Lymphoedema, oedema, oedema at end of life, palliative care, prevalence, risk factors

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The International Lymphoedema Framework has proposed the term ‘oedema at the end of life’ (OATEOL) to cover all forms of oedema that develop as a result of multiple factors relating to terminal illness (International Lymphoedema Framework and Canadian Lymphedema Framework, 2010). While lymphoedema has been a focus of study in palliative care, the multitude of aetiological factors for leg swelling present in any one palliative care patient makes it unlikely that pure lymphoedema exists in this population (Mortimer and Levick, 2004). Even in situations once thought to be pure lymphoedema, for example, those resulting from treatment of breast cancer, arterial and venous flow abnormalities have been measured in addition to lymphatic system damage (Mortimer, 2003). Similarly, so-called

Abstract

Objectives: Oedema at the end of life is an undertreated and burdensome problem in palliative care patients, but its prevalence and association with risk factors is unknown. The authors aimed to investigate the prevalence of lower-limb oedema at the end of life in a palliative care population and measure the associated risk factors. **Methods:** A cross-sectional cohort study was carried out in two palliative care units of pitting lower-limb oedema at the end of life and associated risk factors. This was the first stage of a larger interventional study for treatment of oedema at the end of life in palliative care patients. **Results:** Fifty-nine participants were admitted during the 1-month study period. Of these, 50.8% had pitting oedema in one or both legs on clinical assessment. The mean age was 67.4 years and 64% were male. All patients had at least one risk factor for oedema at the end of life (mean 3.4). **Conclusion:** Lower-limb oedema at the end of life is a common problem in the palliative care population. Early recognition and further research on risk factors may enable the introduction of preventative strategies to reduce the incidence of this burdensome problem.

‘venous disease’, such as leg ulceration, has been found to involve abnormal lymph drainage (Mortimer, 1995). Levick and Michel (2010) concluded that all visible oedema has a lymphatic component. Hence, the introduction of an umbrella term to capture this heterogeneous condition in all its forms.

The risk of developing OATEOL increases with obesity and reduces with physical activity (Paskett et al, 2012). Medication known to cause or exacerbate existing oedema includes calcium antagonists, corticosteroids, non-steroidal anti-inflammatory drugs (NSAIDs), sex hormones and anticonvulsants (International Lymphoedema Framework and Canadian Lymphedema Framework, 2010). OATEOL is commonly seen in many terminal illnesses, such as chronic heart failure, advanced neurological

disease, liver disease, end-stage renal disease, chronic respiratory disease and cancer (Wang et al, 2014). OATEOL has the potential to affect the person’s quality of life adversely, with some people experiencing an impact on their daily life and activities of daily living (Hayes, 2008).

While oedema of the arm following axillary lymph node dissection is probably the most common cause of secondary lymphoedema (Rockson, 2001), this study focused on oedema of the lower limb, about which less is known. The few studies that have explored it have found that the condition is under-recognised and under-treated (Moffatt et al, 2003). Problems in comparing studies and estimates of oedema relate to variation in definition and assessment approaches (Wang and Keast, 2016).

Currently, access to therapists to manage lower-limb oedema is a challenge (Tiwari et al, 2006). Understanding the natural history and prevalence of OATEOL is necessary to define the disease burden and provide adequate resources for its treatment. The aim of this cross-sectional cohort study was, therefore, to ascertain the prevalence of lower-limb OATEOL in an inpatient palliative care population at the time of admission and to measure the associated risk factors, in order to guide future longitudinal research.

Methods

Study population

Palliative care inpatients in two metropolitan palliative care units in Sydney, Australia. This was a heterogeneous group of patients, reflecting the wide referral base for palliative care in Australia.

Study setting

The specialist palliative care inpatient units provide free care for patients with life-limiting illness who have complex physical symptoms or psychosocial needs, with the aim of stabilising these to enable discharge, or to provide ongoing inpatient care for terminal care in the last days of life. Both the units have links to specialist community palliative care teams.

One unit provides care for patients within a 3,245 km² area serving over 800,000 people in South West Sydney, Australia, with 20 inpatient beds and approximately 480 admissions each year. The other unit provides care for patients in Northern Sydney, which serves over 878,000 people, with 20 inpatient beds and approximately 430 admissions each year. There is no emergency department on either campus, but access to general medical beds and an emergency department is available nearby.

Study design and data collection

This was a cross-sectional, consecutive cohort study for the period of one calendar month (June 2013).

Data reported here comprised part of a larger study exploring an intervention for OATEOL in a palliative care population, for which ethical approval was granted by St Vincent's Human Research Ethics Committee (reference: 11/036). Admitting medical officers and/or

physiotherapists assessed patients as part of the established standardised admission procedure in each unit to identify which were eligible for the larger study. Data were extracted from the medical records by researchers to compile de-identified data collection sheets.

All inpatients during the study period were screened for pitting lower-limb oedema through the normal process of admission to the unit. Pitting of the lower limb was assessed by applying sustained pressure for approximately 20 seconds against the medial malleolus and observing for persistent depression in the tissues after removal of pressure. The prolonged pressure time was recommended as the skin changes in lymphoedema can make the tissues less pliable (Mortimer and Levick, 2004). All patients were screened to exclude differential diagnoses, such as deep venous thrombosis and lipoedema.

Researchers collected the following data for each patient with pitting lower-limb oedema: demographic variables (age, gender); clinical variables (palliative diagnosis); description of oedema variables (site at which pitting oedema was present — right leg, left leg, both legs); and longevity (whether greater than 3 months). The extent of oedema was not recorded for the purposes of this sub-study, as this stage of the larger research project merely required documentation of whether OATEOL was absent or present.

Risk factor variables

Medications at the time of admission that promote fluid retention, such as calcium blockers, NSAIDs, corticosteroids, or medications containing oestrogen; anticoagulant use and/or history of venous thromboembolic disease; cancer diagnosis; pelvic or abdominal involvement with tumour; past or current lower-limb cellulitis, ulcer or trauma; organ failure (renal, hepatic, cardiac); hypoalbuminaemia (serum albumin <32 g/L) if performed by the treating team within 3 days of admission; thyroid disease; and obesity. A global measure of functional status defined by Karnofsky (Australian) Performance Scale (AKPS) (Abernethy et al, 2005) was also collected to define level of immobility. AKPS has been developed for use to assess function in palliative care populations, using descriptors suited to palliative care populations.

Analysis

Statistical analyses were performed with the use of SPSS software, version 21.0 (2012). Descriptive statistics were used to estimate the frequencies, means and standard deviations of the study variables. Frequency counts and percentages were used for categorical variables, and mean, range, and standard deviation for continuous variables.

Results

A total of 59 patients were admitted to the two wards during the study time period. Of these, 30 (50.8%) had lower-limb oedema that had been present for at least 3 months. The mean age was 67.4 years (range 38–97, standard deviation (SD) 13.8) and 64% were male. A total of 86.5% had a cancer diagnosis (including thoracic, breast, colorectal and anal, upper GIT, genitourinary and gynaecological). The remainder had cardiac and/or lung failure or neurological disease. Mean AKPS score was 39 (range 20–60, SD 14.8). Clinico-demographic characteristics for the participants and presence of risk factors is shown in *Table 1*. Risk factors were present in all patients with lower-limb oedema (mean 3.4%, range 1–8%, SD 2.7). In this population, the most common risk factors were: cancer diagnosis (83%), medications that promote leg swelling through fluid retention (70%) and AKPS score <40 (63%).

Discussion

In this sample of palliative care patients, over 50% were found to have OATEOL on admission to a specialist palliative care inpatient unit. Of these, all had risk factors for OATEOL, which can be easily screened for on admission. While prognosis was not measured for this sample, the fact that the patients in the sample were admitted to an inpatient unit indicates either advanced disease or severe symptomatology and so would reflect an unusually high level of morbidity even for palliative care patients. This is reflected in the AKPS mean of just over 30, indicating an almost completely bedfast sample. However, this does not detract from the importance of this finding.

This prevalence is considerably higher than that of chronic oedema in the general community. One cross-sectional study of healthcare services in south-west

Table 1. Clinical and demographic characteristics of participants¹.

Characteristic	Outcome (n=30)
Age in years - mean (range, SD)	67.4 (38-97, 13.8)
Male sex	19 (63)
Primary life-threatening illness:	
Cancer	
Thoracic	6 (20)
Breast	3 (10)
Colorectal	2 (7)
Upper GIT	7 (23)
Genitourinary tract	2 (7)
Gynaecological	2 (7)
Other	
Cardiac failure	2 (7)
Neurological disease	2 (7)
Respiratory failure	1 (3)
AKPS² on admission	
60	2 (7)
50	7 (23)
40	4 (13)
30	8 (27)
20	9 (30)
Risk factors on admission³	
AKPS = < 40	19 (63)
Medications promoting fluid retention	21 (70)
Pelvic or abdominal mass and/or lymphadenopathy	7 (23)
Cancer diagnosis	25 (83)
Cardiac, renal or hepatic failure	6 (20)
History of venous thromboembolism	7 (23)
Albumin < 35 g/L	7 (23)
Obesity (BMI > 30 kg/m ²)	3 (8)
Thyroid disease	3 (8)
Lower-limb ulcer, infection or trauma	3 (8)
Varicose veins	0 (0)

¹Values are number (%) unless otherwise indicated. ²AKPS = Australian Karnofsky Performance Scale. Scores range from 0 (worst) to 100 (best). AKPS score of 50–70 indicates a patient is unable to work and requires assistance, score of 0–40 indicates a patient is unable to care for self and requires the equivalent of institutional or hospital care. ³Each participant could have more than one risk factor.

London found a prevalence of 1.33/1,000 (Williams et al, 2004), similar to that found in a Norwegian study with 1.44/1,000 (International Lymphoedema Framework and Canadian Lymphedema Framework, 2010). It is more common than upper-limb

lymphoedema in cancer patients, which has been reported as occurring in 11.0–31.0% women following treatment for breast cancer (Logan, 1995). While little is known about the prevalence of lower-limb lymphoedema in palliative care populations, a study at

an English lymphoedema clinic indicated that approximately 30% of patients referred presented with lower-limb problems (Logan, 1995). According to this study, therefore, OATEOL in palliative care populations represents a more prevalent problem.

The average number of risk factors per patient was 3.4. While some of these risk factors are unavoidable, such as diagnosis and disease distribution, others could conceivably be avoided. In view of the prevalence of OATEOL, more attention needs to be given to use of medications known to promote fluid retention in advanced disease. Similarly, this study supports initiatives to encourage exercise and weight control even in patients with life-threatening disease. In the situation where risk factors are unavoidable, their identification should prompt increased vigilance for detecting the onset of OATEOL.

This study is the first to the authors' knowledge to document the prevalence of lower-limb OATEOL in palliative care inpatients. Strengths of this study include a consecutive cohort, which reduces bias of the prevalence rate, and formal identification of the presence of oedema by a trained physiotherapist/medical officer.

Limitations of this study included the small sample size and the age of the data. However, since the time of data collection, demand on palliative care services in Australia has increased, and led to increased morbidity in the in-patient population, suggesting that any bias present would be to under-estimated the prevalence of this problem. Furthermore, the OATEOL was only categorised by presence/absence and duration, and other important variables that should be measured in future studies include more detailed documentation of the extent of oedema in each patient. Inclusion of upper-body oedema and genital oedema would give a more comprehensive picture of the extent of this problem. While our study assessed the presence of absence of OATEOL only by clinical assessment, many authors suggest its presence is experienced subjectively, as 'heaviness, tightness and pain' (Newman et al, 1996) prior to objective appearance, which would also suggest that any bias in this study would be to underestimate prevalence.

Conclusion

OATEOL often goes undiagnosed and, therefore, untreated, in patients with advanced

disease. These results suggest that lower-limb OATEOL may be a common problem in palliative care patients and that it may be possible to predict which patients will develop this symptom. An understanding of the prevalence of this condition within the palliative care setting is an important factor in increasing awareness among healthcare professionals, which will lead to better management of this condition.

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