

Prevalence of lymphoedema and quality of life among patients attending a hospital-based wound management and vascular clinic

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ABSTRACT

Lymphoedema is a chronic, incurable, debilitating condition, usually affecting a limb and causes discomfort, pain, heaviness, limited motion, unsatisfactory appearance and impacts on quality of life. However, there is a paucity of prevalence data on this condition. This study aimed to determine the prevalence of lymphoedema among persons attending wound management and vascular clinics in an acute tertiary referral hospital. Four hundred and eighteen patients meeting the inclusion criteria were assessed. A prevalence rate of 2.63% ($n = 11$) was recorded. Thirty-six percent ($n = 4$) had history of cellulitis and broken skin, 64% ($n = 7$) had history of broken skin and 36% ($n = 4$) had undergone treatment for venous leg ulcers. The most common co-morbidities were hypertension 55% ($n = 6$), deep vein thrombosis (DVT) 27% ($n = 3$), hypercholesterolemia 36% ($n = 4$) and type 2 diabetes 27% ($n = 3$). Quality of life scores identified that physical functioning was the domain most affected among this group. This study has identified the need to raise awareness of this condition among clinicians working in the area of wound management.

Key words: Lymphoedema • Non-cancer • Prevalence • Quality of life • Wound

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INTRODUCTION

Although groups at high risk for the development of lymphoedema (1,2), such as those with breast cancer, have been studied, little is known about the prevalence or incidence of non-cancer-related lymphoedema and this is particularly so in Ireland. One Irish national survey of lymphoedema services reported that patients with lymphoedema due to immobility, venous disease, tissue damage, infection and inflammation were rated as a much smaller percentage of practitioners caseloads (<5%) than cancer-related or primary lymphoedema (3). Amongst the patients in this study, 6% reported having non-cancer-related secondary lymphoedema, and having waited on average 20.6 months for a diagnosis (3). However, these results are likely to be an underestimate of the prevalence as questionnaires were primarily targeted at palliative care, oncology and physiotherapy practitioners. A report from Northern Ireland with a population of 1.67 million, estimates there are 2257 individuals with lymphoedema (4). In addition, they estimate 20 new cases of primary lymphoedema annually and 200–250 new cases secondary to breast cancer and a further 330–400 secondary to gynaecology and prostate cancer. However, there is little recognition of non-cancer-related lymphoedema within this study and figures presented are estimates.

Patients attending wound management clinics and vascular services may be particularly predisposed to development of lymphoedema as potential risk factors for lymphoedema such as underlying peripheral arterial disease, diabetes, chronic venous insufficiency, are prevalent among this population (5–7). However, the prevalence of lymphoedema among this group has not been assessed.

Lack of recognition of lymphoedema symptoms or inadequate treatment may lead to specific complications such as recurrent cellulitis, infections and lymphangitis (2) requiring hospital admission and incurring considerable costs (8,9). Further damage to the lymphatics occurs because of inflammation, therefore, perpetuating the cycle of recurrent infections and increasing the burden on the quality of life of the patient and the health service. Management aims to decrease or delay the progression of swelling and prevent associated infection. This is usually achieved using a combination

of skin care, external pressure (bandaging or hosiery), isotonic exercise and massage (8).

A rational development of services and ensuring appropriate access to effective therapy that may improve quality of life depends on accurate epidemiological data whilst allowing for comparisons between populations.

AIMS AND OBJECTIVES

Whilst there is a dearth of international prevalence data on non-cancer-related lymphoedema, there is minimal Irish data (3,9). Our study therefore aimed to (i) determine the prevalence of lower limb lymphoedema and associated co-morbidities in a specific hospital outpatient population (patients attending wound management and vascular clinics), (ii) establish whether patients have been diagnosed with or treated for lymphoedema in the past, (iii) test the use of the data collection tool to guide a larger population-based study and (iv) determine the quality of life scores of persons diagnosed with lymphoedema using the SF-36 item health survey.

METHODS

All patients attending outpatient vascular surgery clinics and wound management clinic in an acute 600-bed hospital serving a population of 250 000 persons were included over a 4-week period in July–August 2009. The study protocol conformed to the ethical guidelines of the 1975 Declaration of Helsinki and was approved by research ethics review committee of the study hospital.

Persons suffering from chronic oedema of the lower limb of greater than 3 months duration with or without co-existing leg ulceration were identified. Once identified, consent was obtained for inclusion in the study. Baseline data was collected using a validated case ascertainment questionnaire (10). A clinical diagnosis of lymphoedema was made using the criteria from the UK Lymphoedema Framework and was based on skin assessment plus medical history, history of non-resolution of limb swelling overnight or with elevation, and a positive Stemmer's sign (inability to pinch a fold of skin at the base of the second toe).

The site of oedema was identified using a diagram of anterior and posterior views of the

Key Points

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- lack of recognition of lymphoedema symptoms or inadequate treatment may lead to specific complications such as recurrent cellulitis, infections and lymphangitis requiring hospital admission and incurring considerable costs
- our study is aimed to (i) determine the prevalence of lower limb lymphoedema and associated co-morbidities in a specific hospital outpatient population (patients attending wound management and vascular clinics), (ii) establish whether patients have been diagnosed with or treated for lymphoedema in the past, (iii) test the use of the data collection tool to guide a larger population-based study and (iv) determine the quality of life scores of persons diagnosed with lymphoedema using the SF-36 item health survey
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body. Questions relating to the definitions of lymphoedema were asked, including duration of oedema, complete resolution overnight or on elevation, and history of proven diagnosis or treatment for lymphoedema. All current treatments, if provided, were listed. Data collection was completed by three members of the study team trained in lymphoedema assessment using the previously validated case ascertainment instrument from the UK Lymphoedema Framework.

Eleven patients with lymphoedema and two patients with chronic oedema of the lower limb were invited to, and completed, the SF-36 item health survey. Although two people did not have lymphoedema, the chronicity of their oedema supported the decision to include them in the quality of life study. All questions are scored on a scale from 0 to 100, with 100 representing the highest level of functioning possible. Aggregate scores are compiled as a percentage of the total points possible. The scores from those questions that addressed each specific area of functional health status were then averaged together for a final score within each of the eight dimensions measured. The SF-36 is a well-validated tool to assess the quality of life and allows for meaningful comparisons with the Irish National Dataset (11).

RESULTS

Over the 4-week study period, 542 patient attendances at the vascular surgery and wound management outpatient clinics were recorded. Of these, 418 unique patient attendances were noted; the remaining 124 were return visits. Of the 418 patients, males predominated in a ratio of 3:1, 66% ($n = 275$) male versus 33% ($n = 143$) female. Two hundred and fifty-four patients attended the vascular clinics (63% male) and 164 patients attended the wound management clinics (70% male) with the wound management clinics having a higher incidence of repeat attendances.

In total, 20 patients (4.78% of all attendees) presented with limb swelling (95% lower limb) but 3 of these were because of short duration and recent onset cardiac failure. Of the 17 with chronic (>3 month) leg swelling, 11 fulfilled predetermined criteria for lymphoedema (8 patients from the vascular clinic; 3 patients from the wound management

clinics) yielding an overall prevalence of 2.63% in this population (1.8% wound management clinics, 3.14% vascular clinics). More males than females were diagnosed with lymphoedema (67% versus 33%). The average age was 65 years (range 46–85). None of these 11 patients had previously been diagnosed with or treated for lymphoedema despite an average duration of lower limb swelling in these patients of 2.9 years. Seventy-three percent ($n = 8$) had oedema present >1 year and 18% ($n = 2$) for >9 years indicating that these patients have chronic oedema rather than a transient problem. None of the patients were in receipt of any lymphoedema related services or treatments.

In the 6 months prior to the study, of those 11 newly diagnosed with lymphoedema, 36% ($n = 4$) had history of cellulitis and broken skin, 64% ($n = 7$) had history of broken skin and 36% ($n = 4$) had undergone treatment for venous leg ulcers.

The most common co-morbidities among the 11 patients were hypertension 55% ($n = 6$), deep vein thrombosis (DVT) 27% ($n = 3$), hypercholesterolemia 36% ($n = 4$) and type 2 diabetes 27% ($n = 3$).

Thirteen patients completed the SF-36 health survey. Physical functioning was most affected by lymphoedema with emotional well-being the least affected. Physical functioning mean scores (54%), role limitations due to physical health (47%), role limitations due to emotional problems (62%), energy/fatigue (57%), emotional well-being (76%), social functioning (73%), pain (61%) and general health (57%).

Data were compared with the minimum Irish dataset (11) and the difference was statistically significant for all domains ($P < 0.005$) except emotional well-being which was higher for individuals in our study than the Irish dataset.

DISCUSSION

This study is the first to quantify the prevalence and quality of life of lymphoedema in vascular and wound management services in Ireland and provides an insight in the health status of this group. Whilst this is a small study, the findings provide valuable information on the characteristics of the population attending these services and will be invaluable in designing a larger study.

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The average age of the patients was consistent with evidence from the literature that there is an increase in the incidence with age (8). In contrast to other studies, our results indicate an increased prevalence in men (67%) but this may be a direct reflection of the higher number of males in the overall population cohort (66%).

Results from this study suggest that awareness and therapeutic knowledge about lymphoedema is particularly poor. None of the patients in this study had been told they had lymphoedema or had received treatment for limb swelling despite an average duration of lower limb swelling of 2.9 years. Although this study represents a small sample from a skewed population, the findings concur with other surveys and somewhat reflect the limited availability of diagnosis and treatment throughout the country and indicates the great necessity for further wide-scale epidemiological studies of this condition (3). Indeed, little has changed from a previous study which identified the characteristic of new referrals to 27 lymphoedema treatment units (12). In the latter study, patients with non-cancer-related lymphoedema had suffered the condition disproportionately longer than the cancer-related group ($P < 0.001$) in addition to greater numbers having bilateral swelling ($P < 0.001$).

The patients identified with lymphoedema had a high incidence of co-morbidities – notably vascular disease with concurrent venous leg ulceration and diabetes. This is not surprising given the type of clinics included in the study. However, there are no prior published data detailing the prevalence of individuals diagnosed with both lymphoedema and diabetes. Our study shows that 27% ($n = 3$) had type 2 diabetes. Because of the small numbers the results should be treated with caution and the findings cannot be extrapolated to represent all persons with lymphoedema. Nevertheless, this raises some issues for consideration as a review by McIntosh and Green (13) have suggested that with respect to the lower limb that a combination of lymphoedema and diabetes compromise the viability of the legs and feet, placing the individual at high risk of infection, ulceration and necrosis, and, in severe cases, the loss of a limb.

The prevalence of skin problems including cellulitis, broken skin and leg ulceration among those in our study is very high. It supports

previous research (8) in which 29% ($n = 64$) of patients experienced at least one acute infection in the affected area over the previous year with 16 experiencing more than three episodes during this time (8). Of those experiencing acute infections, 27% ($n = 17$) were admitted to hospital for intravenous antibiotics. The high percentage of patients with skin breakdown and infection in 6 months prior to the study and in whom lymphoedema was previously undiagnosed may indicate a lack of awareness among clinicians of the condition. This is in keeping with other studies in which 47% of patients presenting with cellulitis of the lower limbs were diagnosed with lymphoedema, none of whom had a previous diagnosis of same (9). This would suggest there is a need for increased education and training among clinicians working in wound management services on how to diagnose and manage lymphoedema.

Results on the quality of life data are comparable with other studies in which physical limitations due to lymphoedema was the lowest score and emotional well-being the highest score (14). The small sample size reduces generalisability of results but some issues are worth considering. The reduction in physical activity is concerning as mobility and activity are particularly important to aid venous return and improve tissue perfusion which in turn can aid wound healing. This is further compounded by the poor energy and levels of fatigue reported by participants which can negate against activity and mobility. A positive response was reported for emotional well-being and social functioning which is important as it reduces the possibility for social isolation which is frequently reported by persons with ulceration (15,16). It is a curious finding in our study and that of Franks *et al.* (14) that these individuals can still record highest scores for emotional well-being having multiple co-morbidities and chronic long standing lower limb swelling and all in a health system which did not diagnose their lymphoedema and for whom resources are below par.

Lymphoedema is a chronic, incurable, debilitating condition, usually affecting a limb and causes discomfort, pain, heaviness, limited motion, unsatisfactory appearance and impacts on quality of life (14,17–19). All efforts must be pursued to improve the quality of life

Key Points

- results from this study suggest that awareness and therapeutic knowledge about lymphoedema is particularly poor
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Key Points

- the World Alliance for Wound and Lymphoedema Care (WAWLC) predicts that because of the growing epidemic of noncommunicable disease and longer life expectancy, the prevalence and impact of chronic wounds and lymphoedema are likely to increase until we are aware of the incidence and epidemiology of the condition in Ireland and an effective coordinated therapeutic strategy is developed that will identify and treat lymphoedema at an early stage in its course, lymphoedema is likely to remain an unnecessary burden on the patient's life, the health service and the economy

and prevent complications for this group of patients.

FUTURE PROJECTIONS FOR LYMPHOEDEMA

The World Alliance for Wound and Lymphoedema Care (WAWLC) (20) predicts that because of the growing epidemic of noncommunicable disease and longer life expectancy, the prevalence and impact of chronic wounds and lymphoedema are likely to increase. Although not specific causative factors, obesity, diabetes and vascular disease are among the potential risk factors for lymphoedema and a range of government and international reports would suggest that these are increasing (21,22). In addition, the advances in the diagnosis and treatment of cancers and increased cancer survivorship will undoubtedly impact on the numbers of people with lymphoedema.

At this point, one can only speculate the numbers of people with lymphoedema in Ireland. Extrapolating from the South West London study of 1.33 per 1000 population (8), we might expect the current number of cases in the Republic of Ireland to be in excess of 5500 [4.2 million population (23)]. This is a significant number of people, many of whom are currently not in receipt of appropriate management. It is important therefore, that accurate prevalence data is obtained with the goal of improving services and management strategies for people with lymphoedema. Until we are aware of the incidence and epidemiology of the condition in Ireland and an effective coordinated therapeutic strategy is developed that will identify and treat lymphoedema at an early stage in its course, lymphoedema is likely to remain an unnecessary burden on the patient's life, the health service and the economy.

CONCLUSION

The prevalence of non-cancer-related, lower limb lymphoedema of 2.63% among patients attending vascular and wound management services is quite high. Lymphoedema is frequently unrecognised and awareness of the condition should be improved. This data indicates that the number of patients in Ireland with undiagnosed and untreated lymphoedema is likely to be substantial and further investigation is warranted to

identify and treat these patients at an earlier stage. Lymphoedema affects all aspect of the individual quality of life with physical functioning being most affected.

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