

Obesity-related lymphoedema and hospice charities: considerations for the future

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Key words

Charity, funding, hospice, lymphoedema, obesity

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Declaration of interest: None.

There is a high prevalence of lymphoedema among those who are obese (Fife and Carter, 2008). As obesity is increasingly common, obesity-related lymphoedema is likely to be seen more frequently. These patients are placing an increasing burden on healthcare services and the NHS. They often require input from many different services as inpatients, as outpatients and in the community (Lewis and Morgan, 2008).

In 2003, the estimated number of lymphoedema patients in the UK was 100,000 and the prevalence of this condition increases with age (Moffat et al, 2003). The estimated number of such patients would be higher today due to not only the ageing population but also to other contributing factors, such as obesity (Lifestyles Statistics Team, Health and Social Care Information Centre, 2015). Obese patients often have multiple comorbidities and can be unwell for many years. This combination creates pressure on lymphoedema services.

As with any treatment or service, there needs to be consideration of cost, outcomes

Abstract

The Leicestershire Organisation for the Relief of Suffering (LOROS), a hospice-based charity, runs a lymphoedema service and is facing an increase in the number of referrals for the treatment of obesity-related lymphoedema. This article highlights the issues involved and questions the appropriateness of providing treatment for this cohort of patients when the majority of funding is through charitable donations. This is a consideration when planning the strategic direction of the clinic and for lymphoedema services as a whole.

of treatments and the sustainability of the potential benefits. The source of funding should also be taken into account. The limited resources available both within the NHS and the charitable sector mean that any service must be cost effective. When funds include those from voluntary donations there is an added responsibility to ensure that the service is the one that the donors intended to support.

Given the increasing burden on lymphoedema services to manage obesity-related lymphoedema, this article reviews the role a charitable lymphoedema service plays for these patients and the challenges of using charitable resources for such a service.

Charitable lymphoedema services in the UK

There are currently approximately 150 lymphoedema treatment services in the UK according to the directory on the British Lymphology Society website (2017). From the information available online, 63 of these appear to have charitable funding and state

that they treat lymphoedema 'secondary to other causes'.

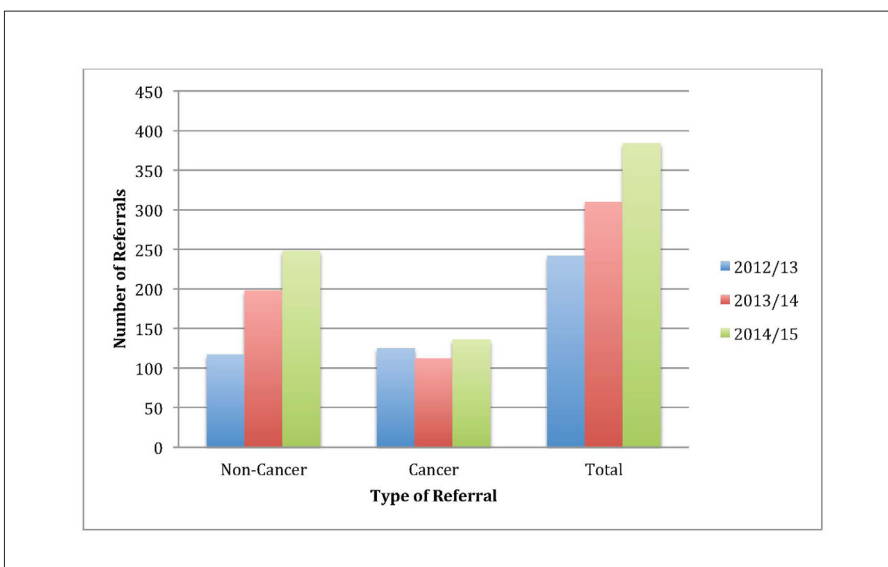
Case study: LOROS

The Leicestershire Organisation for the Relief of Suffering (LOROS) is a charitable hospice serving a population of around 1 million people across Leicestershire and Rutland. Every year LOROS Hospice cares for >2,500 people living in the area it covers, and >1,700 patients a year are seen by the lymphoedema service. Approximately 70% of funding is from donations and the remaining 30% is derived from the NHS for all of the services provided by the hospice.

The LOROS lymphoedema service was established in 1995 for those with cancer-related lymphoedema and expanded to include primary lymphoedema in 1997 due to local demand and increasing referrals as there was nowhere locally for these patients to receive the expertise offered by the lymphoedema clinic. It is an outpatient service based within the hospice. Since the expansion to cover non-cancer-related lymphoedema, there has been a gradual

Table 1. Referrals to the LOROS lymphoedema service.

New referrals	Financial year		
	2012/13	2013/14	2014/15
Non-cancer:			
• Number	117	198	248
• Percentage	48%	64%	65%
Cancer:			
• Number	125	112	136
• Percentage	52%	36%	35%
Total referrals	242	310	384

**Figure 1.** Numbers of patients with and without cancer-related lymphoedema referred to LOROS.

increase in the proportion of non-cancer patients, and most recently in bariatric patients. The proportion of new referrals for non-cancer-related lymphoedema increased from 48% in 2012/13 to 65% in 2014/15. The total number of referrals to the service, particularly non-cancer-related referrals, is also increasing each year, see *Table 1* and *Figure 1*.

The caseload in August 2015 was 891 individuals: 330 (37%) of these patients had cancer-related lymphoedema and 561 (63%) patients had non-cancer-related lymphoedema. Two-hundred-and-eighty-eight patients (32%) had a body mass index >40 kg/m² and 734 (82%) had a body mass index >30 kg/m². Figures in December 2016 were very similar to those from 2015: the total caseload was 859 individuals, of which 359 (42%) were cancer patients and 500 (58%) were non-cancer patients.

As with any service, there must be ongoing review to ensure that it develops

to meet needs and puts limited resources to the best use.

Financial challenge

There are a number of challenges related to funding healthcare for obesity-related lymphoedema (Lewis and Morgan, 2008; Cooper, 2014). Funding for this treatment is via NHS services in some areas and through charitable organisations — often hospices — in others.

LOROS, for example, spends around £7.5 million each year on patient care, of which approximately £4.5 million is derived through fundraising. The lymphoedema service must be mindful of the moral responsibility to spend donations appropriately in a way that those who have contributed would expect. When supporters give money to the charity there is an element of trust. People donate because of the established

reputation of the organisation and demonstration that it is well run and valued locally. The Board of Trustees oversee the distribution of funds and how well these are spent. Supporters can look at hospice finances through the Charity Commission website. The hospice writes a quality account in the public domain and shares information in newsletters and the hospice strategy is publically available.

The annual cost of the lymphoedema service is approximately £230,000. This has remained static over the years. In the financial year to December 2016, it was £227,530. The estimated costs of the services provided are given in *Table 2*.

There are particular cost implications for the treatment of obese patients. The specialist equipment, such as bariatric chairs and couches, means further costs. There is also often the need for two members of staff to assist with moving the patient and with bandaging. The hosiery may be more expensive, as obese patients often require styles that are not available on prescription, (e.g. certain styles of made-to-measure hosiery), and supplying these is a continual outlay for the hospice. In addition, some patients may require two layers of hosiery and new hosiery if their weight changes. As a result of these changing or challenging requirements, morbidly obese patients cannot be discharged, staying on the caseload for many years until they become too infirm to attend the clinic or die, often from their comorbidities. In comparison, patients with secondary lymphoedema who are not morbidly obese are discharged on average within 2 years. Patients may also have other difficulties, including abdominal aprons. These require wraps or bespoke compression garments and are a further long-standing expense to the clinic. Although some funds are provided by the Clinical Commissioning Group (CCG), they do not cover the ever-increasing cost of the non-cancer cohort of patients.

Considerations for the future

A recent service development at LOROS looked at potential approaches for treating bariatric patients, including a multidisciplinary clinic with a dietitian. The patients attending all had more than one comorbidity, in keeping with oedema

often being multifactorial (Wilkins et al, 2014). There is evidence that treatment with bandaging has long-term benefits, provided this is associated with sustained weight loss (Fife and Carter, 2008). Despite this, the patients attending the clinic were reluctant to take dietetic advice and continued support to help them lose weight and improve outcomes (Wilkins et al, 2014). For those patients not engaging in weight loss, there is little or no evidence for maintained benefit with lymphoedema treatment (Todd, 2009). Bariatric patients require ongoing psychological and dietetic support (Stignant, 2009), which is beyond the remit of this clinic. There is a local pathway funded through CCG monies to access bariatric services.

The cost of treatment in terms of time and money is significant. For example, an average below-knee circular knit stocking suitable for the majority of non-morbidly obese patients costs about £33 per pair, whereas a morbidly obese patient often requires a flat knit made-to-measure stocking with a grip top and/or zip costing as much as £83 per stocking. In this era of difficult funding decisions, questions should be asked:

- Should such a service continue if benefit is limited?
- Should a charitable fund for palliative care continue to offer this service?
- Would those donating to the hospice wish their money to be spent on providing these services?

In addition, there is an increasing awareness that this patient cohort does not align to the mission of the charity: “LOROS is a charity whose aim is to enhance the quality of life of adult patients with cancer, progressive neurological conditions and end-stage organ failure for whom curative treatment is no longer possible.” These considerations have influenced the direction of the clinic.

Table 2. Service treatment costs.

Treatment	Details	Cost
Outpatient department	First appointment	£180
	Follow-up appointment	£120
Course of bandaging	Per session, excluding costs of material (each patient can require 2–5 sessions for 2–3 weeks)	£120–£180

Service developments to move treatment into the community

For those patients who are housebound, an outpatient service such as that provided at LOROS has little to offer. There are possible clinical benefits and potential cost savings to be made through the treatment of patients in the community (Lewis and Morgan, 2008). Outpatient services include ongoing review at home with timely interventions in the management of cellulitis and concurrent comorbidities, such as heart disease, respiratory disease, renal impairment and diabetes, thus avoiding multiple hospital appointments and acute hospital admissions.

Given the increasing burden on specialist services, there are plans to improve the ability of non-specialists to manage chronic oedema within the community. There is an incentive to fund such services as the community care would potentially lead to cost savings for both for the specialist service – a new patient lymphoedema clinic appointment costs £180, follow-up £120, plus hosiery costs – and hospitals through a reduction admissions (Lewis and Morgan, 2008). The estimated cost of an acute hospital bed is £400 per day, depending on the location and services needed (Department of Health, 2015). The charity is working collaboratively to establish and support community teams.

Conclusion

The number of patients with obesity-related lymphoedema is increasing. There are clinical and financial challenges in managing these patients within the limited resources available. The future direction of the clinic needs to ensure that the money from charitable donations is spent in the most effective way. Community- or home-based services are likely to be increasingly important and a role for the service needs to be found within these structures.

Any service should be effective and efficient, providing treatment with sustainable outcomes to as many people as possible while offering value for money. In charitable organisations, there is the added moral responsibility to use donated funds in the most appropriate way and in a manner that donors intended, aligned to charities’ missions and values.

References

British Lymphology Society (2017) *Directory*. Available at: <http://www.thebls.com/directory/> (accessed 06.06.2017)

Cooper G (2014) Practical barriers to achieving self-management of lymphoedema. *Br J Community Nurs* 19(10 Suppl): S14–20

Department of Health (2015) *NHS Hospital Stay*. Available at: <https://data.gov.uk/data-request/nhs-hospital-stay> (accessed 17.05.2017)

Fife CE, Carter MJ (2008) Lymphedema in the morbidly obese patient: unique challenges in a unique population. *Ostomy Wound Manage* 54(1): 44–56

Lewis M, Morgan K (2008) Managing chronic oedema: a collaborative community approach. *Br J Community Nurs* 13(4): S25–32

Lifestyles Statistics Team, Health and Social Care Information Centre (2015) *Statistics on Obesity, Physical Activity and Diet. England 2015*. Health and Social Care Information Centre. Available at: www.hscic.gov.uk/catalogue/PUB16988/obes-phys-acti-diet-eng-2015.pdf (accessed 17.05.2017)

Moffat CJ, Franks PJ, Doherty DC et al (2003) Lymphoedema: an underestimated health problem. *QJM* 96(10): 731–8

Stignant A (2009) Tackling obesity as part of a lymphedema management programme. *Br J Community Nurs* 14(10): S9–12, 14

Todd M (2009) Managing chronic oedema in the morbidly obese patient. *Br J Nurs* 18(18): 1120–4

Wilkins C, Swain G, Cooke C (2014) Facing up to the obesity crisis: outcomes of a bariatric lymphoedema clinic. *Journal of Lymphoedema* 9(2): 27–9