

## Management of Lower Limb Lymphoedema in the United Kingdom

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**Objective.** Many investigations and treatments exist for lower limb lymphoedema. We undertook a survey on the management of this condition by vascular surgeons and the resources available for its treatment in the UK.

**Design.** A questionnaire was designed to assess the management of lymphoedema.

**Materials and method.** A postal questionnaire was sent to all members of the The Vascular Society of Great Britain and Ireland.

**Results.** 251/440 (57%) consultant surgeons returned a completed questionnaire comprising 45.3% teaching hospital and 54.7% district general hospital (DGH) consultants. 77.9% of the consultants saw less than 10 patients annually with lymphoedema. The commonest causes of lymphoedema were primary lymphoedema (99.3%) and malignancy (37.1%). Lipoedema, a cause of limb swelling was only seen or recognised by 46.2% of the consultants. The commonest investigations performed were a duplex scan, lymphoscintigram, full blood count and urea and electrolytes. The common methods of confirming lymphoedema were either by lymphoscintigram (54.5%) or from a diagnosis of exclusion (33.7%). Lymphoedema physiotherapy was available only to 53.8% of the consultants. Surgery was performed by 10.5% of consultants. 73.4% of the consultants believed that lymphoedema is managed inadequately and 72.9% believed that resources are insufficient in the UK for this condition.

**Conclusion.** In the UK the majority of vascular consultants see less than 10 patients annually with lymphoedema. Very few patients undergo confirmation of this diagnosis with non-invasive investigation and very few consultants perform surgery. Management of this condition is perceived by the consultants to be poor, with a lack of resources and particular shortage of lymphoedema physiotherapists. Centralisation of these services may be a way of improving this condition.

**Keywords:** Lymphoedema; Lipoedema; Lymphoscintigram; Complex physical therapy; Surgery; Resources.

### Introduction

Lymphoedema is a swelling of an area (or of a segment) of the body due to an accumulation of lymphatic fluid.<sup>1</sup> Arm lymphoedema is typically seen following axillary surgery for breast carcinoma and is managed mainly by breast multidisciplinary teams. The commonest causes of lower limb lymphoedema are primary lymphoedema and malignancy (treatment including surgery and radiotherapy). Specialist lymphoedema practitioners, dermatologists or vascular surgeons manage lower limb lymphoedema in the UK. Because of its relatively benign nature, the treatment of lower limb lymphoedema is not always high priority. This is because of the more urgent arterial cases and in

comparison to arm lymphoedema, a lack of resources as breast cancer is relatively better funded.

The pioneers of the most effective treatment of lymphoedema, i.e. physiotherapy was developed in Germany by Foldi's who have treated a considerable number of patients in their clinic. However, there is very little data on the resources and management of lower limb lymphoedema in the UK and other European countries. In this survey, our aim was to study at the management of lower limb lymphoedema in the UK by vascular surgeons as well as assessing the resources available for treating this condition.

### Method

A questionnaire was developed on the management of lymphoedema based on a recent review of this condition by the authors.<sup>1</sup> This was then sent to all

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members of the vascular society from the database supplied by its chief executive. The questionnaire had the approval of the honorary secretary of the Vascular Society. Five hundred and forty questionnaires were sent out. A pre-paid reply envelope was included.

## Results

Two hundred and seventy three members returned a completed questionnaire. These included 251 from consultants (response rate 57%) and 22 from other groups (radiologist, registrars and nurses, response rate 22%). Our interest was the management of this condition by vascular consultants and thus the results are presented for this group only. These comprised 122 (45.3%) teaching hospital consultants and 147 (54.7%) district general hospital consultants (DGH). Eighteen consultants worked in both DGH and teaching hospitals and the results of these have been analysed in both groups.

### Workload of consultants

This is summarised in Fig. 1. The majority of consultants estimated that they saw less than 10 new patients with lymphoedema every year (73.7% teaching hospital, 82.2% DGH). This is thus a small proportion of a typical consultant workload.

### Cause of lymphoedema

Typical causes of lower limb lymphoedema in the Western world are primary lymphoedema, malignancy and post-arterial reconstruction. The commonest cause of lymphoedema in our survey was primary lymphoedema (seen as a cause in at least one patient by 100% teaching hospital consultants and by 98.6% DGH consultants). Other causes of lymphoedema in the survey were malignancy

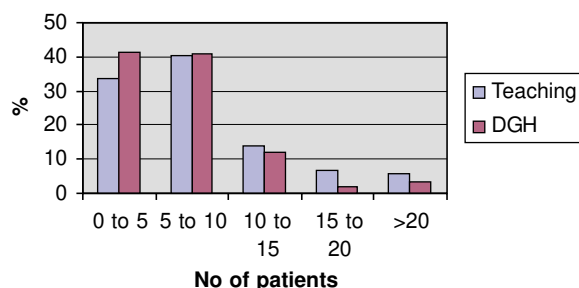


Fig. 1. No of patients seen annually with lymphoedema. DGH, district general hospital.

(seen as a causal factor by 36.1% teaching hospital consultant and 38.1% DGH consultant) and following arterial reconstructions (seen by 19.7% teaching hospital consultants and 17% DGH consultant). Other causes for lymphoedema were following cellulitis, venous disease and venous surgery or post radiotherapy. This was seen by 10.7% of teaching hospital consultants and 6.8% district general hospital consultants. Filariasis, the commonest cause of lymphoedema worldwide was rarely seen, as only five teaching hospital consultants described it a cause of lymphoedema in their patients. Other causes of lymphoedema, which were not seen in the survey, include trauma and burns. It is worth noting that a proportion of patients with abnormal lymphatics but without clinical disease only present with lymphoedema following an abnormal event such as surgery or trauma.

### Recognition of lipoedema

Lipoedema (lipomatosis of the leg) is a symmetrical enlargement of both legs with sparing of the feet.<sup>2</sup> It is a cause for referral of patients with suspected lymphoedema. This condition is less widely treated, in our survey where only 47.7% teaching hospital and 44.7% of DGH consultants recognised or saw this condition. The median numbers of lipoedema cases seen were 3 (1–50) and 2 (1–20), respectively.

### Initial investigation of patients presenting with lymphoedema

The results are summarised in Fig. 2. Other investigations ordered included abdominal ultrasound and computed tomographic scan of the pelvis.

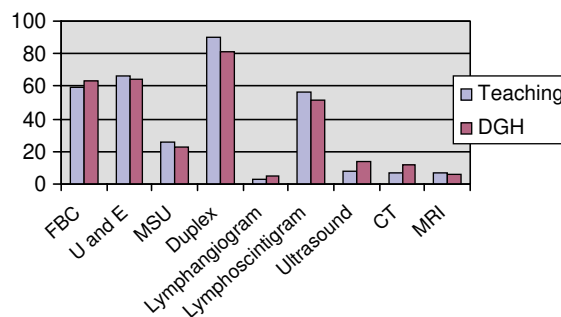
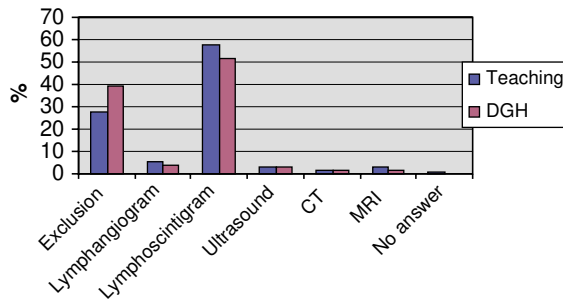


Fig. 2. Initial investigations in patients with suspected lymphoedema. FBC, full blood count; U and E, urea and electrolytes; MSU, mid stream urine; CT, computed tomography; MRI, magnetic resonance imaging.



**Fig. 3.** Investigations for the confirmation of lymphoedema. DGH, district general hospital; CT, computed tomography; MRI, magnetic resonance imaging.

#### Confirmation of lymphoedema

The results are summarised in Fig. 3. The gold standard for confirming lymphoedema is a lymphoscintigram.<sup>3</sup> The advantage of a lymphoscintigram is that it is well tolerated, provides images of lymphatics and lymph nodes as well as evaluation of lymph transport. The main problem with lymphoscintigram has been its variable sensitivity and specificity. This depends on the time the image is taken, i.e. in some series if early films are not done then the lymphatic abnormality may not be seen. In others, if delayed films are not done, up to 24 h post injection, then the abnormality may be missed. Some of these flaws have been overcome by the use of semi-quantitative score such as the modified Kleinhans score.<sup>4</sup> Lymphoscintigram cannot also differentiate between primary and secondary lymphoedema.

Non-invasive investigations including computed tomography (CT), magnetic resonance imaging (MRI) or even ultrasound will show characteristic features related to the skin changes associated with lymphoedema but will not show the anatomical abnormality of the lymphatics. A lymphangiogram is only indicated if surgery is being considered and is rarely used now.<sup>5</sup> This is because lymphangiogram is painful, requires a skin incision and has the added risk of hypersensitivity reaction and emboli.

#### Treatment of lymphoedema

Lymphoedema treatment involves a multidisciplinary approach.<sup>6</sup> This would include a vascular surgeon, a lymphoedema physiotherapist, a dermatologist and vascular nurses. However, the patient can usually be managed after confirmation of the diagnosis by a lymphoedema physiotherapist. Initial treatment after investigation and diagnosis involves complex physical (decongestive) therapy.<sup>7-9</sup> This treatment is carried out by lymphoedema physiotherapist, who only were

available for 55.8% of teaching hospital consultants and 51.7% DGH consultants. The initial treatment by all consultants was either to put patients into compression hosiery or if available refer for lymphoedema physiotherapist. One consultant offered heat/microwave therapy and another offered surgery as initial treatment. Only two consultants from a DGH offered drug treatment for lymphoedema though the agents used were not specified. There is at present time no effective available drug treatment for lymphoedema. Benzopyrones were previously shown to be effective for this condition but a recent Cochrane review by Badger *et al.* found that the trials were of poor quality and, therefore, no firm conclusion could be drawn on the effectiveness of this group of drugs.<sup>10</sup> Coumarin has been withdrawn in many countries because of reports of hepatotoxicity.<sup>11,12</sup>

#### Surgical treatment

14.8% of teaching hospital consultants and 6.1% of DGH consultants undertook surgery for lymphoedema. The procedures performed are highlighted in Table 1.

#### Overall management and resources for treatment of lymphoedema

The majority of consultants (75.4% of teaching hospital consultants and 71.4% of DGH consultants) expressed a view that this condition was not managed adequately whilst 5.7% of teaching hospital and 9.5% of DGH consultant thought it was managed adequately; the remainder did not know. In terms of resources 73.8% teaching hospital and 72.1% DGH consultants thought there was a lack of resources whilst 4.9 and 7.5% of teaching and DGH consultants, respectively, thought it was sufficient.

#### Discussion

Lower limb lymphoedema is a chronic disorder where the most important part of the management is

**Table 1.** Types of surgical procedures performed by consultants for lymphoedema

Procedure	Teaching hospital (n = 122)	District general hospital (n = 147)
Liposuction	2	5
Charles	7	5
Homan	15	5
Shunt	4	1
Other	1	0

diagnosis and symptomatic control. However, because of this chronicity, it is generally not given enough importance and likely to, therefore, suffer from lack of resources, which may lead to poor management.

It is estimated that there are around 100,000 patients in the UK with lymphoedema. Our survey shows that few of these patients are seen being referred to a vascular surgeon and may reflect the lack of importance and knowledge for this benign but often debilitating condition. Moffatt *et al.* surveyed the South West London community, which has a dedicated lymphoedema service and found that 36% of patients were not receiving any treatment for their lymphoedema.<sup>13</sup> Also in their survey, vascular surgeons were seeing only 24% of the patients but this was likely because of the good lymphoedema service provided at the local teaching hospital by lymphoedema practitioners. Therefore, it is likely that in the UK vascular surgeons are seeing more than 24% of all patients with lymphoedema and that it is again likely that more than 36% of patients are not receiving any treatment is an underestimate when applied to the overall population of the UK.

The commonest investigations in patients referred with lymphoedema included blood and urine analysis, venous duplex scanning and lymphoscintigraphy. The rationale for blood and urine analysis is that the differential diagnosis of lymphoedema may include many systemic diseases such as congestive cardiac failure, liver failure, renal failure and protein losing enteropathy. It is for this reason that in some patients where it may be difficult to differentiate between lymphoedema and systemic cause for leg swelling then blood tests and urine analysis are important.

The venous duplex scan in a patient with lymphoedema may show superficial or deep venous reflux but this may not actually be the cause of the limb swelling.<sup>14</sup> Venous reflux may be secondary to the lymphoedema and vice versa. Therefore, if after this investigation only, patients are surgically treated for their venous reflux then their lymphoedema may worsen.<sup>15</sup> So it is important to be careful about interpretation of venous reflux in patients with limb swelling.

In terms of confirming the diagnosis, 28–40% of the consultants diagnosed lymphoedema by exclusion. There were still a high proportion of patients undergoing lymphoscintigraphy to confirm diagnosis and a real lack of use of other non-invasive investigation, which can make the diagnosis in most cases.<sup>1</sup> A combination of lymphoscintigraphy and lymphangiography will be still be needed is surgery is being planned.

The most effective treatment of lymphoedema is complex decongestive therapy. In the UK only 52–56% of consultant vascular surgeon had access to this. It is thought that only 5% of patients with lymphoedema will be suitable for surgery. What we found in our survey was that some consultants would refer patients for possible surgery to regional or national units whilst many are never referred patients for surgery. This could be leading to many patients who would have benefited from surgical treatment being denied this because of the opinion of that surgery is not successful. There are three main types of surgical procedure, liposuction, debulking operations and bypass procedure.<sup>16–18</sup> Liposuction has been used with promising results but mainly in arm lymphoedema. There are four well-known debulking procedures, Homan's, Charles, Servelle's and Thompson's. All give variable results and complications are common and serious. Very few centres worldwide undertake bypass procedures and again results are variable. Because of the specialised nature of this type of surgery and the low numbers of patients who are suitable for surgery, few consultants undertake it and this was reflected in our survey.

Overall, a majority of consultants found that this condition is poorly managed and there is a lack of resources in the UK. The small number of patients seen by each vascular consultant, the lack of lymphoedema physiotherapist or nurses, the lack of awareness of lipoedema and lack of referral may be improved by centralising the treatment and by educating the community doctors. This would then be cost effective in terms of funding a lymphoedema specialist and may also lead to more patients being referred for surgery to improve their quality of life. As discussed in the introduction about the lack of data from European countries on the resources and management of lower limb lymphoedema, further work should involve a survey of the European vascular consultants.

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