

# LYMPHOEDEMA EDUCATION NEEDS OF CLINICIANS: A NATIONAL STUDY

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## Abstract

**Background:** Poor knowledge of lymphoedema among clinicians can delay its management, increasing the burden on affected individuals, carers, and services. **Aims:** To determine the nature of, and means to address, lymphoedema education needs of clinicians within the context of their working lives. **Methods:** Electronic surveys of lymphoedema specialists and generalist clinicians in Scotland, followed by focus group discussions. **Results:** Gaps in knowledge and constraints imposed by referral criteria to specialist services contribute to a feeling of professional impotence among both generalists and specialists, as they are unable to provide consistency of care across different care settings. **Conclusions:** Clinicians have unmet education needs that are profession and healthcare setting specific. Information technology has the potential to improve lymphoedema knowledge, care, and managing patients with lymphoedema. **Declaration of interest:** The University of Glasgow provides post-registration courses for clinicians to specialise in lymphoedema.

A full report of this study is available on request from NHS Education Scotland at: <http://tinyurl.com/LymphEducReport>

## Key words

Clinician  
Education  
Lymphoedema  
Technology

Long-term condition management is a current national health policy priority (NHS Scotland, 2010) and, consequently, has received increasing research and service development attention, particularly in primary care (O'Brien et al, 2011). In comparison to more common long-term conditions, lymphoedema has received little attention outside

the field of cancer care (Moffatt et al, 2003). Yet recurrent infections and advanced lymphoedema care impose significant costs on individuals, their extended social networks, and health and social care services (Todd et al, 2010). Early identification (Stout et al, 2008), physiotherapy (Torres et al, 2010), and patient education (Fu et al, 2008) have been shown to prevent or reduce symptoms in breast cancer-related lymphoedema.

Inequities in specialist lymphoedema service provision and unmet educational needs among clinicians have previously been reported in Scotland (Bulley, 2007; Sneddon et al, 2008). However, the nature of this need for different professional groups across different healthcare settings is not currently known. Therefore, the aim of this study was to determine the nature of, and means by which to address, educational needs relating to lymphoedema among clinicians in Scotland, within the context of their working lives.

## Methods

The study was underpinned by a post-positivism paradigm, utilising both quantitative and qualitative methods of data collection and analysis in two distinct but complementary phases. The first phase comprised electronic surveys of lymphoedema specialists and registered clinicians who had no specific training regarding lymphoedema (referred to hereafter as generalists). SurveyMonkey ([surveymonkey.com](http://surveymonkey.com)) was used due to its simplicity and data security (Cline, 2010).

Survey questions were derived from the literature and early scoping exercises, and piloted with clinicians outside Scotland and with UK educationalists and researchers working in the field of lymphoedema. The surveys elicited information in relation to lymphoedema on the respondents' current role, previous learning, unmet educational needs, and preferred learning modes. Respondents were also asked to indicate their willingness to be

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contacted for the next phase of the study. A copy of the survey given to generalists is available at <http://www.surveymonkey.com/s/lymphoedemasurveycopy>. A copy of the specialists' survey is available at <http://www.surveymonkey.com/s/specialistscopy>.

The second phase of the study comprised focus group discussions with a purposeful sample of survey respondents to gain additional insight to the survey findings. The study population comprised clinicians employed, or contracted, to provide patient care in primary care, community care, hospices and outpatient services in Scotland.

No incentives were offered for participation.

### Surveys

The surveys were cascaded to the relevant clinicians via the Scottish Lymphoedema Practitioner Network, the Chief Nurse for Scotland, the Lead Allied Health Professional (AHP), GP Local Medical Committees and the Scottish Partnership for Palliative Care. Although, ward-based hospital staff were not specifically excluded, the generalist survey was directed specifically towards GPs, nurses and allied health professionals, working in primary care, community care, outpatient clinics, oncology, and palliative care.

The initial request to participate in the survey was followed by two reminders at fortnightly intervals.

Survey data were collected between 1 and 28 February, 2011. SPSS version 19 statistical software (IBM; Portsmouth, UK) was used for descriptive statistical analysis.

### Focus group discussions

The initial analysis of survey data informed the interview guide for the focus group discussions. Participants were purposefully selected to achieve the greatest representation of professions and health boards.

The discussions were facilitated by one of the authors (AON) and field notes were taken by another (RD). Two focus group discussions were conducted between 12 and 19 May, 2011. The discussions were audio-taped and subsequently transcribed verbatim. Transcripts were analysed independently by the authors (RD, AON, and BF).

Ethical approval as educational research was given by the University of Glasgow Medical Faculty Ethics Committee in January 2011. The return of completed questionnaire was considered as implied consent from respondents, while written informed consent was obtained from all focus group participants.

### Results

Thirty-six of the 54 lymphoedema specialist practitioners in Scotland (67%) responded to the specialist survey. Four-hundred-and-ninety-eight generalists responded to the generalist survey: 218 were community nurses (44%), 71 were acute/specialist doctors and nurses (14%), and 209 were AHPs (42%).

All but one health board were represented in the sample. It not possible to describe the survey response rates by individual professional groups due to the cascade design.

Almost two-thirds of the lymphoedema specialist respondents (64%) had  $\geq 4$  years' experience of working in their specialist role. Almost two-fifths of respondents (39%) spent at least 40% of their working time as a lymphoedema specialist, and almost three-quarters (74%) had protected time for their work as a lymphoedema specialist. Just over half of the respondents (53%) practiced solely in hospital or hospice care settings, 8% worked only in community or residential care settings, and 29% worked across all of these care settings.

The large majority of generalist

respondents (79%) indicated that their role in lymphoedema care was limited to referral to another service or professional, and almost two-thirds (64%) indicated that their role was identification of possible lymphoedema. Only 7% indicated that they played no role in lymphoedema care.

### Self-identified education needs Lymphoedema specialists

Almost two-thirds (64%) of lymphoedema specialist respondents reported that their educational needs were completely or mostly met, and the same proportion reported that they had undertaken lymphoedema training in the previous 2 years.

Respondents who had completed this training were more likely than those who had not to report that their training needs had been completely or mostly met (82% cumulative frequency (CF) 42%,  $p < 0.05$ ). Just over one-third of respondents (36%) identified a training need for the future, in relation to latest innovations.

One-quarter of respondents (25%) identified future training needs to be manual lymphatic drainage and differential diagnosis. Between one-fifth and one-tenth identified needs in relation to service development and management; teaching/supporting other clinicians; simple lymphatic drainage massage (patient self-massage); genital oedema; oedema in advanced disease; related dermatology issues; supporting self management; and wound/ulcer care.

### Generalists

Only 70 (14%) generalist respondents had undertaken some form of education on lymphoedema diagnosis and management over the past 5 years. Four-hundred (80%) generalists reported at least one subject of education needed regarding lymphoedema. Specifically, over half indicated a need for education on current management techniques (53%), and over a third indicated differential diagnosis (46%), assessment of chronic oedema (36%), and skin care to reduce

the risk of cellulitis (35%).

In subsequent analysis, generalists were grouped into 'acute/specialist doctors and nurses', 'community doctors and nurses' and 'AHPs'. **Figure 1** illustrates the relationship between the educational needs of clinicians in relation to healthcare setting self-identified by more than a third of each group.

In the 'acute/specialist doctors and nurses' group only, current management of lymphoedema was identified as a need by over a third of respondents. By contrast, more than one-third of community doctors and nurses identified needs in relation to current lymphoedema management, differential diagnosis, assessment of chronic oedema, skin care and care of lymphoedema in advanced disease (**Table 1**).

Group analysis showed that community nurses were more likely than community doctors to report a need for education on lymphoedema-related wound/leg ulcer care (56% CF 15%,  $p < 0.001$ ).

Physiotherapists, meanwhile, were more likely than other AHPs to identify exercise prescription (57% CF 22%,  $p < 0.001$ ), while podiatrists were more likely than other AHPs to identify skin care to prevent cellulitis (55% CF 20%,  $p < 0.001$ ).

### Specialists

Twenty-eight lymphoedema specialist respondents (78%) perceived other clinicians had educational needs in relation to lymphoedema. For the purposes of this report, acute/specialist doctors and nurses group includes hospital and hospice doctors and nurses and breast care nurses. The community doctors and nurses group includes community/district nurses, practice nurses, and GPs. The AHPs group includes physiotherapists, podiatrists, occupational therapists, dieticians, orthotists, radiographers and pharmacists. Where there are significant within-group differences they are highlighted.

In relation to acute/specialist doctors and nurses, more than half of lymphoedema specialists perceived educational needs relating to lymphoedema in acute oncology (53%), current best management (61%), identification of patients at risk of developing lymphoedema (67%), and skin care (64%). In addition, over a third identified the need of differential diagnosis (42%), and management of oedema in advanced disease (36%).

In relation to community doctors and nurses, more than half of the lymphoedema specialists perceived educational needs relating to current best management (64%), differential diagnosis (58%), identification of patients at risk (61%), wound/ulcer care (69%), and skin care (53%). Over a third identified needs relating to assessment of chronic oedema (39%) and measuring for compression garments (33%). However, there were differences within this group; more than two-thirds of specialists identified wound/ulcer care as a particular need of community/district nurses, rather than GPs (69% CF 8%,  $p < 0.001$ ).

In relation to AHPs, over a third of lymphoedema specialists identified educational needs relating to skin care (58%), exercise (50%), identifying patients at risk (47%), and current best management (44%). Group analysis showed that the specialists' main perceived education need for physiotherapists was exercise prescription for lymphoedema (50%) and for podiatrists was skin care to reduce risk of cellulitis (50%).

Thus, current management, skin care to reduce cellulitis risk, and identifying patients at risk were perceived as areas of educational need for all three professional groups by at least one-third of lymphoedema specialists (**Figure 2**).

### Methods for addressing educational needs

In relation to their own educational needs concerning lymphoedema, almost three-fifths of generalists (59%) indicated that it would be useful for the education to be delivered by a local lymphoedema practitioner.

### Key points

- » All generalist clinicians had unmet educational needs relating to differential diagnosis and current best management of lymphoedema.
- » Other unmet lymphoedema-related educational needs were profession- and healthcare setting-specific.
- » Poor knowledge of lymphoedema and limited access to specialist services were a source of frustration and feelings of professional impotence among generalists.
- » Telehealth and information technology were identified as having the potential to address some unmet educational needs and improve access to specialist services.

Around two-fifths indicated that it could be usefully addressed by online learning (44%), while a similar proportion (38%) indicated that education in the healthcare setting would be useful.

Only one-tenth of generalist respondents (10%) indicated a higher education institution as being useful in meeting their lymphoedema education needs, and even fewer (7%) indicated product suppliers. There were no significant within-group or single-profession variances. In relation to their own educational needs, up to two-thirds of lymphoedema specialists indicated the usefulness of a range of information technology media (**Table 2**).

### Focus group discussion findings

The emergent themes from the focus group were categorised into those that provided the context for education need and those that were of direct relevance to lymphoedema education. Funding issues were interwoven within the individual themes in each of these broad categories.

The inter-related themes

**Table 1**

**Reported educational needs of clinicians by professional group (excluding lymphoedema specialists)**

Lymphoedema educational need	Number (%) of respondents		
	Acute/ specialist doctors and nurses	Community doctors and nurses	Allied healthcare professionals
Current management	25 (35)	140 (64)	99 (47)
Differential diagnosis	20 (28)	128 (59)	80 (38)
Exercise	8 (11)	33 (15)	86 (41)
Head and neck	4 (6)	32 (15)	12 (6)
Identification of risk	11 (16)	66 (30)	58 (28)
Acute oncology	4 (6)	31 (14)	13 (6)
Advanced disease	19 (27)	87 (40)	36 (17)
Compression garments	4 (6)	19 (9)	17 (8)
Pneumatic pumps	1 (1)	18 (8)	6 (3)
Teach self massage	10 (14)	36 (17)	53 (25)
Wound/ulcer care	13 (18)	65 (30)	30 (14)
Skin care	19 (27)	91 (42)	66 (32)
Bandaging for lymphoedema	6 (8)	23 (10)	10 (5)
Bandaging in advanced disease	4 (6)	20 (9)	9 (4)
Assessment of chronic oedema	12 (17)	109 (50)	57 (27)

concerning the context to the educational need included: the rewards of managing lymphoedema; lymphoedema as a hidden and sometimes buried problem; professional impotence; service boundaries; and lymphoedema specialist resource scarcity.

Generalists encountered barriers to accessing specialist services and educational opportunities, while lymphoedema specialists were frustrated by their inability to ensure continuity of appropriate care in the community. Identified patient need was not always met, and described as sometimes 'buried', due to concerns about existing services being overwhelmed.

Here are a selection of interesting

quotes from various participants in the focus groups:

"My boss is worried that it would open a whole can of worms if I got involved too much in lymphoedema and we don't have the funding to back it up... I wasn't allowed to tell anyone I had been on it [study days], just in case the referrals started coming through because we really can't support a lymphoedema service added on to everything else."

**Group 2, Tissue Viability Nurse**

"I think one of the problems is, for me, and GPs perhaps, that you think 'is there much that can be done?'"

Sometimes, if you recognise the problem, you have to do something, otherwise why pick up the problem... Huge frustrations for us... I think

sometimes it's whose role it is in health care, and I guess one thing about general practice is, you have to look after the people on your list... we did have one physiotherapist but she really restricted her services to people with breast cancer, and the problem is, with people coming to the surgery, if people are mobile-ish then our district nurses won't treat them, so we involve the practice nurses who have less experience with that. So we struggle to know what to do with them really. There is very little specialist service."

**Group 2, GP**

Three inter-related themes concerning the educational need emerged: the differing needs of groups of individuals, education providers, and education media. The generalist clinicians' educational needs related to difficulties they encountered in all stages of the patient journey, including establishing a diagnosis and delivery of care.

"[It would be positive] if we were better educated in who to refer to, and at what stage to refer, what to look out for, how to recognise signs and symptoms."

**Group 1, Podiatrist**

"I don't [feel prepared] at all. As a tissue viability nurse, as I said, just mopping up really... all I've done on the lymphoedema side of things is go on the 2-day awareness course."

**Group 2, Tissue Viability Nurse**

"[Clinicians] need to be getting the education in earlier, at student nurse level".

**Group 2, Tissue Viability Nurse**

"[I'd like to see this incorporated at undergraduate level] because it's something you see a lot, no matter what level you are at."

**Group 1, Podiatrist**

Both groups concluded that developing a background level of knowledge during undergraduate training would be beneficial.

Lymphoedema specialists expressed the value of formal specialist training, which was then supplemented by shadowing, networking, and opportunities for updating skills.

“Having now done two or three modules, I feel a bit more equipped. With networking as well... you learn lots just from patient mileage and speaking with others in the peer group.”

**Group 1, Lymphoedema Specialist**

A range of potential providers were identified to address educational needs including higher education institutions, local lymphoedema specialists and product suppliers. The value of accredited academic courses for specialising was related to credibility, in terms of strengthening ability to influence practice.

“It’s always better to have formal training when you are in a small speciality, for other people to acknowledge what you do... to be listened to.”

**Group 1, Lymphoedema Specialist**

Lymphoedema specialist-led training for generalists was perceived as beneficial

**Table 2**  
**Perceptions of lymphoedema specialist respondents of the potential for technology to enhance lymphoedema education**

Type of technology	Number of respondents (%)
Teaching podcasts	25 (69)
Web-based problem solving	24 (67)
DVD masterclass	24 (67)
Web-based self assessment	22 (61)
Live web access to tutor	21 (58)
Web-based student discussion forum	21 (58)
DVD modular assessment by accredited organisation	20 (56)
DVD modular self-assessment	19 (53)
Web-based assessment by accredited organisation	19 (53)
Telehealth masterclass	12 (33)

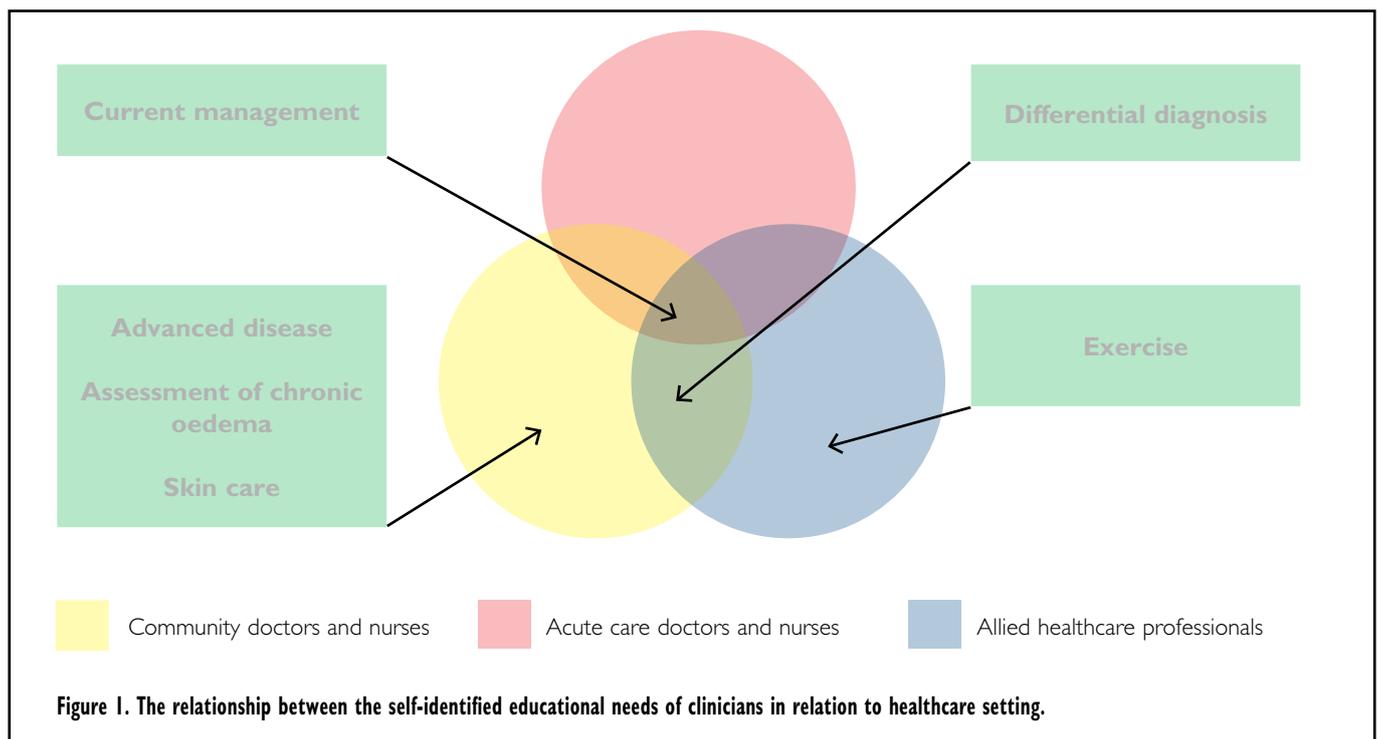
by generalists and lymphoedema specialists. However, patient caseload and geographical spread of lymphoedema specialists presented barriers to the delivery of local educational events. Disappointingly, lymphoedema specialists who had offered such training reported poor uptake:

“We ran three [specialist-led

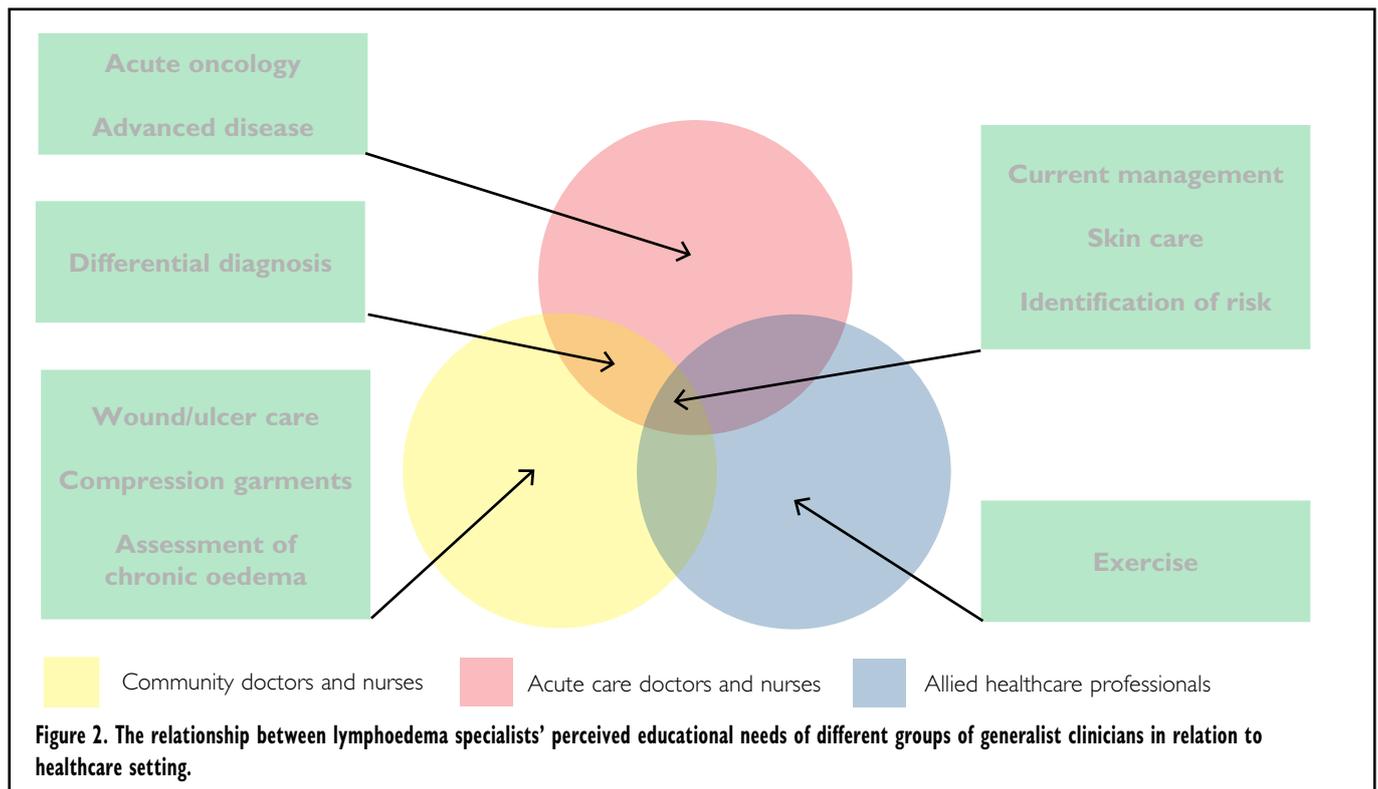
courses] for GPs, on their own, in the evening with hot food and everything; we had one response for three attempts. That was with the points you get for GP study days.”

**Group 1, Lymphoedema Specialist**

The potential for greater use of technology for education was acknowledged, but it was also acknowledged that it has its



**Figure 1. The relationship between the self-identified educational needs of clinicians in relation to healthcare setting.**



limitations:

“I think it's that skills element. It's good to do the reading, the theory, the evidence part of it, but there is something of the skills of a specialist, and (that's) what you then get. The creating of a network is important to maintain those skills.”

**Group 2, Cancer Nurse Consultant**

**Discussion**

This study not only confirmed the findings of Sneddon et al (2008), that clinicians have unmet educational needs relating to lymphoedema, but also found that these are specific to professional groups and healthcare settings. Lack of knowledge and constraints imposed by referral criteria to specialist services contribute to both generalists and specialists feeling professionally impotent and unable to provide consistency of care across care settings. Clinicians expressed concern that the problem was, at times, buried, through fear that services would be overwhelmed by referrals, and of the impact this would have on individual service budgets.

Specialists who had attempted to provide educational events at a local level for generalists reported poor uptake rates and regional embargoes on working with industry. The reasons for poor attendance are likely to be multifactorial and include the relative low profile of lymphoedema and competing priorities, constraints relating to time, funding, and study leave.

The idea of inclusion of lymphoedema in undergraduate medical and other clinician training was well supported and is a current theme of discussion internationally through the Education Forum of the International Lymphoedema Framework (2012).

**Limitations**

The results of this study are based on clinicians in Scotland and so further research is required to establish their applicability to other healthcare settings in the UK.

Another limitation of the study was that the distribution of the surveys relied on third parties. However, this was a condition of

the ethical approval of this study to ensure the anonymity of the study participants. Practice nurses were under-represented in the sample due to the means of questionnaire distribution as they are employed directly by the GP practices and not by the health boards. A further study of this group would be beneficial to determine educational needs that are specific to them.

**Implications**

Increased knowledge and awareness of lymphoedema among GPs and other clinicians may enable earlier identification and treatment. NHS and GP intranet informational resources should contain guidance on differential diagnosis and best practice in relation to the treatment and management of lymphoedema, and information about local services, including their referral criteria. In the meantime, greater awareness would be useful of existing online learning resources for clinicians, such as the Lymphoedema Support Network and *British Medical Journal* collaboration (<http://learning.bmj.com/learning/module-intro/lymphoedema-.html?moduleId=10029385> and [www](http://www)).

lymphormation.org).

The low number of practice nurses represented in this study was also a limitation. Given that district nurses only provide care for house-bound patients, while practice nurses provide care for patients who are sufficiently mobile to attend the GP practice, future research is required to compare and contrast knowledge and experiences of these two groups of primary care nurses in regard to lymphoedema educational needs.

Technology brings opportunities, not only online learning modules for those wanting specific education or an update in lymphoedema, but also for clinical learning experiences. Teleconference-style consultations have been used in other specialties using a remote specialist to provide clinical support for less experienced specialists and generalists and could provide a form of peer support and review (Whelan and Wagner, 2011).

Such developments would align well with current NHS Scotland initiatives (Scottish Centre for Telehealth and Telecare, 2011), but would need robust evaluation of impact. In addition, telehealth technologies provide opportunities to network with lymphoedema experts nationally or even internationally.

Providing the resources to give generalists access to a network of experts could reduce the professional impotence they experience when trying to care for this patient group. This has the potential to overcome some of the service fragmentation problems caused by current service design and referral criteria, which are provider-led rather than needs-led.

## Conclusion

Clinicians have specific educational needs regarding lymphoedema, particularly in relation to differential diagnosis and current best practice. A lack of knowledge on lymphoedema, combined with limited access to specialist services was

identified as a source of frustration, feelings of professional impotence, and perceived suboptimal patient management.

There was support for the inclusion of lymphoedema in clinicians' undergraduate training. Telehealth and information technology have the potential to address some unmet educational needs and improve access to specialist services.

Lymphoedema education content and delivery can be better designed with this improved understanding of the nature of the educational needs of clinicians and their preferences for education media within the context of their working lives.

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