An Investigation of the Education Needs of Health Care Professionals in Scotland in relation to Lymphoedema Care

Executive Summary

Full report available on NHS Education for Scotland website http://www.nes.scot.nhs.uk/

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Disclaimer:
The views expressed in this report are based on the author’s interpretations of the research findings and may not necessarily reflect those of NHS Education for Scotland or Macmillan Cancer Support

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Glossary of Terms

For the purpose of this report, key terms are defined:

<table>
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<td><strong>Oedema</strong></td>
<td>is a symptom of venous with/without lymphatic system failure which manifests as the presence of excessive fluid in or around cells, tissues or serous cavities of the body, causing localised swelling with or without other symptoms including pain, skin and tissue changes or functional limitations in the affected area.</td>
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<td><strong>Chronic Oedema</strong></td>
<td>is oedema of 3 or more months duration</td>
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<td><strong>Lymphoedema</strong></td>
<td>is both a symptom and a condition. As a symptom, lymphoedema is oedema caused an overload failure of the lymphatic system. As a condition, lymphoedema is the failure of the lymphatic system itself that results in oedema. Lymphoedema can be either a primary or a secondary condition</td>
</tr>
<tr>
<td><strong>Lymphoedema Specialist Practitioners</strong></td>
<td>are health care professionals who have undertaken post-registration education in lymphoedema and/or whose job description includes a specific role in relation to lymphoedema, job titles may include lymphoedema practitioner, lymphoedema key worker, lymphoedema specialist, or advanced lymphoedema practitioner.</td>
</tr>
<tr>
<td><strong>Generalist Health Care Professionals</strong></td>
<td>are health care professionals who have not undertaken post-registration education in lymphoedema, although they may be specialists in their own field e.g. oncology.</td>
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1. BACKGROUND

It is estimated that around 7,000 people in Scotland are affected by lymphoedema (Moffatt et al 2003). If so, there will be 7 patients with lymphoedema registered in an averaged-sized Scottish GP practice (NHS Scotland 2010). The prevalence of lymphoedema is expected to rise in Scotland due to improved cancers survival rates and increases in obesity rates and the population, particularly in the elderly in whom prevalence is higher.

Lymphoedema causes chronic swelling, usually of limbs but may affect the face, genitalia or breast. It can cause discomfort, pain, loss of function and psycho-social problems (Morgan, Franks & Moffatt 2005). Lymphoedema is incurable and, without treatment, is progressive (Lymphoedema Framework, 2006). Delayed treatment can lead to complications, increasing the burden on health and social services (Todd, Harding, & Green 2010). Against this background, it is imperative that all non lymphoedema-specialist health care professionals (HCPs) are able to give contemporary and accurate advice, support treatment and management and, when appropriate, to make referrals to a lymphoedema specialist.

The overall aim of the study was to identify the educational needs in relation to lymphoedema of lymphoedema specialists and generalist HCPs in Scotland and how identified need might best be addressed.

2. METHODS

The study was approved by the University of Glasgow Medical Faculty Ethics Committee. It was underpinned by a post positivism paradigm, utilising both quantitative and qualitative methodologies.

Throughout February 2011, data were collected by electronic questionnaire surveys of lymphoedema specialists and HCPs. The recruitment strategy for the surveys is summarised in Appendix A. The questionnaires elicited information on respondents’ qualifications and, in relation to lymphoedema,
experiences of patient care, perceived educational needs, previous training and views on future access to education. Data were analysed using descriptive statistics to explore associations between variables.

During May 2011, these data were enhanced by qualitative data obtained from two focus group discussions, which were facilitated by an experienced researcher. Participants of these were purposively selected based on profession and health board. The discussions were audio-taped and transcribed verbatim. These were subjected to thematic analysis.

3. RESULTS

In total 534 health care professionals in Scotland responded to the surveys, all but one small health board were represented. Thirty-six of a known population of 54 lymphoedema specialists in Scotland (67%) responded to the specialist survey. Four hundred and ninety-eight Health Care Professionals (HCPs) responded to the generalist survey: 218 community doctors and nurses (44%), 71 acute/specialist doctors and nurses (14%) and 209 allied health professionals (42%).

Fourteen respondents subsequently attended one of two focus group discussions. The first comprised 4 lymphoedema specialists and 2 generalist HCPs, and the second had 2 lymphoedema specialists and 6 generalist HCPs. Each group had representation from at least 4 Health Boards and a range of professions in acute and community health care settings.

3.1 Lymphoedema Specialist Survey Findings

Almost two-thirds of the respondents (64%) had 4 or more years experience of working as a lymphoedema specialist. Virtually all (92%) had undertaken post-registration education on lymphoedema, most (73%) at an advanced level at a Higher Education Institution. Almost two-thirds (64%) reported that they had attended lymphoedema update training in the previous 2 years.
3.1.1 Lymphoedema Specialists Self-Identified Education Needs

In relation to their own needs for education, the top ranked areas of lymphoedema specialists were recent innovations in lymphoedema; supporting self management; managing related dermatological problems; and wound care (Table 1).

Table 1. Top Ranked Self Identified Educational Needs of Lymphoedema Specialists:

<table>
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<th>Topic for Future Education</th>
<th>% of Lymphoedema Specialists Indicating Educational Need</th>
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<tr>
<td>Recent innovations in lymphoedema</td>
<td>36%</td>
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<tr>
<td>Supporting self management</td>
<td>19%</td>
</tr>
<tr>
<td>Managing related dermatological problems</td>
<td>19%</td>
</tr>
<tr>
<td>Wound care issues</td>
<td>17%</td>
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3.1.2 Lymphoedema Specialists Perceptions of the Education Needs of Generalist HCPs

In relation to lymphoedema specialists' perceptions of the education need for generalist HCPs, the top ranked areas were current management; skin care; and identifying patients at risk. Other identified areas were specific to the care setting of the HCP (Figure 1).

Figure 1. The relationship between the lymphoedema specialists’ perceived educational needs of different groups of generalist health care professionals in relation to health care setting.
3.1.3 Lymphoedema Specialists Views on Accessing Future Education
The continued role of Higher Education Institutions (HEIs) in delivering education was considered essential in maintaining quality standards. Two-thirds of respondents believed access to future education could be enhanced by technology. Virtually all (91%) indicated that the most significant enabler to access lymphoedema training was support from managers.

3.2 Generalist HCPs Survey Findings
Of the 498 generalist HCPs responding to the survey, most indicated that their role regarding lymphoedema was referral to specialist services (79%) and identification of lymphoedema (64%). Only 7% indicated that they had no role with lymphoedema.

3.2.1 Generalist HCPs Self-Identified Educational Needs
Four hundred respondents (80%) indicated at least one area of education need regarding lymphoedema. The top ranked areas were current lymphoedema management (53%); differential diagnosis (46%); assessment of patients with chronic oedema (36%); and skin care (35%). There was little overlap in the identified areas for education in relation to the different professional groups in different health care settings (Figure 2.).

![Figure 2. The relationship between the educational needs of different groups of generalist health care professionals in relation to health care setting.](image-url)
Within group analysis showed that the key area for education was wound/ulcer care for community nurses (47%), exercise for physiotherapists (57%) and skin care for podiatrists (55%). Whilst this confirmed the views of the specialists, overall the generalists identified fewer educational needs.

3.2.2 Generalist HCPs Views on Accessing Future Education
Few generalist HCPs perceived a role for HEIs in meeting their educational needs (10%), and even fewer perceived a role for industry (7%). The most frequently ranked means for accessing education were local lymphoedema specialists (59%); on-line learning (44%), and training within health care settings (38%). There were no significant differences in these rankings between or within different HCP groups.

3.3 Focus Group Discussions Findings
The two broad themes emerged from analysis of the focus group discussion were context related and educational need related. Issues relating to funding were interwoven within individual themes in each of these broad categories. Within the context related theme, the issues identified related to the rewards of managing lymphoedema; lymphoedema as a hidden and sometimes buried problem; professional impotence and service boundaries; and local lymphoedema specialist resource scarcity. These are discussed in the full report. Within the education need related theme, the issues identified related to differing needs of individuals; education providers; and education media.

3.3.1. Different Education Needs of Individuals
Patients/carers, generalist HCPs and specialists were identified as groups that had different educational needs.

In relation to the needs of patients and carers, both generalist HCPs and specialists discussed difficulties in knowing the quantity and timing of information giving to patients and carers; suggesting that the subject may need revisiting several times on the patient journey.
Generalist HCPs described the difficulties they experienced establishing a diagnosis; delivering care and long term management; and accessing specialist services, particularly for patients who did not have a cancer diagnosis. Developing a background level of knowledge during undergraduate training was seen as beneficial.

Specialists described the initial motivation to pursue formal specialist training and the need to supplement it with shadowing, networking and seeking varied opportunities to update skills.

3.3.2 Education Providers
It was evident that those who had participated in educational events perceived these valuable. However opportunities for undertaking formal education were perceived to be limited in the current financial climate for both specialists and generalists.

For specialists, the perceived value of accredited courses at university not only related to skills and knowledge but to the credibility of qualification in terms of strengthening their ability to influence practice.

For generalist HCPs, in-house hands-on training by lymphoedema specialists was viewed as beneficial. However, the sheer volume of the patient caseload and geographical spread of lymphoedema specialists was described as a barrier to the delivery of local educational events..

3.3.3 Education Media
There was acknowledgement of the potential for greater use of technology in education, learning gained during remote teleconference consultations and self-paced on-line learning. Limitations of technology for hands-on skills were also discussed. Mentoring and shadowing concurrent with providing patient care was seen as useful to generalists and specialists.
4. DISCUSSION

This study adds to existing evidence on the educational needs in relation to lymphoedema by identifying the nature of these and the means of addressing them within the context of working lives.

Access to specialist lymphoedema services is inequitable. Consequently, both generalists and specialists feel professionally impotent and unable to provide consistency of care across care settings. Whilst gaps in service provision remain, generalists should give serious consideration to becoming better educated in the care and management of their patients with lymphoedema. The implementation of a specialist resource at a Community Healthcare Partnership level would fit well with a national plan which recognises the need to integrate care delivered by health, social care and voluntary organisations (Scottish Government, 2009).

Remaining current with innovations in the field was a key concern of lymphoedema specialists. This reflects the increased rate of research and publication in lymphoedema over the last few years. Over 10 years ago the lack of robust evidence foiled efforts to develop a SIGN guideline for lymphoedema, it may be timely to revisit this.

Increasing difficulties in attending courses was identified by both specialists and generalist HCPs. For specialists, this threatened the valuable role of Higher Education Institutions in providing accredited training. There was a generally positive attitude towards greater use of technology to provide both clinical support and educational opportunities. Such developments would align well with current NHS Scotland initiatives (Scottish Centre for Telehealth and Telecare 2011).

Generalists educational needs concerned current management, identifying lymphoedema or those at risk, and skin care to prevent cellulitis. Recent research found that patient morbidity and health care cost are significantly reduced with early diagnosis and management (Todd, Harding & Green 2010; Stout, Pfalzer, Springer et al, 2012). The suggestion of integration of
lymphoedema education in relation to these areas in to undergraduate medical and other HCP education was well supported.

The perceived need for increasing patient/carer education fits the thrust of recent policy which encourages partnership arrangement between service provider and service users to manage health and long term conditions (Long Term Conditions Alliance 2008 and Scottish Government 2010). The need for education for paid social carers may not have been previously identified and would require cross-agency working.

A study limitation was that questionnaire distribution relied on third parties. However, representation achieved from the target professions was good. It was limited by the recruitment strategy which did not include practice nurses as they are employed by GPs rather than health boards and therefore not included in the information cascade system used. Given that practice nurses, rather than district nurses, provide care for patients who are sufficiently mobile to attend the GP practice, it would have been useful to compare the need of these two groups of healthcare providers.

5. **CONCLUSIONS AND RECOMMENDATIONS**

Health care professionals have specific lymphoedema educational needs and believe these could be met by a number of means including online resources supporting more traditional models of face-to-face contact. The recommendations made take account of the context in which the professionals who participated in the study work.
5.1 Education Need of Lymphoedema Specialists

Research and development in lymphoedema has increased significantly in the last few years. HEI accredited education and regular CPD of specialists was perceived as maintaining best and safe practice.

Recommendations:

1. Lymphoedema specialists should continue to be supported by their managers in maintaining their specialist skills and knowledge by attending relevant HEI and CPD courses.
2. Succession planning should be incorporated into job plans to ensure continuity of service.
3. An expert group should be reconvened to produce a robust evidence-based clinical guideline for the care and management of patients with lymphoedema aiming for acceptance as a SIGN guideline.

5.2 Educational Needs of HCPs

HCPs not specialising in lymphoedema need education in recognising and managing lymphoedema, and information about specialist services and education opportunities. Most of the needs identified by generalist HCPs related to their health care setting and/or professional role.

Recommendations:

1. Recognition of lymphoedema and its contemporary management should be included in all pre-registration/undergraduate HCP education.
2. Continuing education for all generalist HCPs should include the topics of current management in lymphoedema, skin care to prevent cellulitis, identifying those at risk and information on accessing specialist services.
3. Further research is recommended to identify educational needs in relation to lymphoedema of practice nurses, social care providers and unpaid carers.
5.3 Delivery of Future Education

There was an expectation that local specialist practitioners could provide in-service training particularly in practical skills e.g. bandaging. However, there was a perception that educational opportunities were limited due to financial and time constraints. Technology brings an opportunity to create a virtual network of lymphoedema expertise nationally thereby supporting the specialists and generalists. One to one advice on complex cases was seen by specialists and generalists as useful to immediate patient care and effective education; such consultation could be provided virtually. As indicated above, Specialist education is best delivered at HEI.

Recommendations:

1. Specialist Lymphoedema Education and CPD should continue to be available through HEI and accessible to qualified health care professionals working with this patient group.

2. A national network of lymphoedema specialists should be created based around a core website for communication and sharing of resources.

3. The specialists’ role in supporting, acting as resource and educating at a local level should be explicit in job descriptions and job plans allowing time to implement structured training plans.

4. HCPs should have dedicated time to attend in-service training provided by local lymphoedema practitioners based on local need.

5. Generalist HCPs should have access to information on current best practice of lymphoedema through NHS and GP intranet systems including a link to national cellulitis guidelines, information about the referral criteria of specialist services and patient sources of support and information.

6. Awareness should be raised of the online resource on Chronic Oedema/Lymphoedema (differential diagnosis and current management) through BMJ learning

6.4 The Context in which the Educational Needs were Identified

The findings of this study cannot be separated from the context in which healthcare professionals provide care and exposes an inequity of access to specialist lymphoedema care in many parts of Scotland. Lymphoedema is perceived not only as an often unrecognised and under reported problem, but also one that is deliberately ignored due to fear of overwhelming services and the resultant impact on the budget of individual services. Macmillan Cancer Support is currently funding a two year post of Lymphoedema Project Manager who will work with Scottish Health Boards to develop and implement a national policy on lymphoedema.

Recommendations:

1. Consideration should be given to the creating systems for local generalist HCP to have virtual consultations with a lymphoedema specialist.

2. Scottish Health Boards should use the opportunity to work with the Macmillan Lymphoedema Project Manager to review the current model of service provision with a view to providing access to high quality care to patients regardless of underlying cause.

3. Community Health Care Partnerships should consider providing access to a lymphoedema specialist as a source of advice for all community-based generalist HCPs.
References


Appendix A.

The Recruitment Strategy for the Surveys.

Questionnaires were distributed by sending an electronic link to a central hub for each main group of professionals. For the lymphoedema specialist practitioners this was the Scottish Lymphoedema Practitioners Network. The generalist HCPs questionnaire had four main routes: for GPs via the National General Medical Services (GMS) Programme to local GP sub-committee (LMC representatives). For nurses via the Chief Nurse for Scotland and similarly for AHPs via the AHP Lead for Scotland, both directing it particularly to nurses and AHPs who worked in community, out-patient clinics or oncology & palliative care. In order to capture some of the doctors and other HCPs working in hospices the web-link was also distributed through Scottish Partnership for Palliative Care (SPPC), an umbrella organisation for palliative care services in Scotland.

Figure A. Dissemination of questionnaires and number of responses