Scoping the Education Needs of Health Care Professionals regarding Lymphoedema.

Lymphoedema Conference
Durham, March 2013.

Rhian Davies,
Macmillan University Teacher and
PhD research student
Pretext to the Research question

• What are the education needs of Health Care Professionals regarding Lymphoedema?
  – Is there a need?
  – What does it matter?
  – Who says? Are they aware they have a need?
  – Can they say what that need is specifically?
  – How could that need be met in a practical and accessible way?
Background and aims of the study

Previous studies have highlighted an education need in generalist Health Care Professionals and Lymphoedema Practitioners.

(Lam et al 2006; Bulley 2007; Sneddon et al 2008; Simmons 2010; Armer et al 2010)

Delayed referrals, seen too late, earlier diagnosis is easier and cheaper to manage .................

To establish the specific education needs of different Health Care Professionals (HCPs) across Scotland and their preferred method of accessing education.

Supported by NHS Education for Scotland (NES) and Macmillan Cancer Support
Mixed methods study: triangulation of surveys and focus groups.

Firstly two concurrent electronic national surveys:
1. Lymphoedema practitioners
   – Own educational needs and how is this best met?
   – What do other Health Care Professionals need regarding lymphoedema/chronic oedema and could it be met?

2. Generalists
   – What is your educational need regarding the prevention & management of lymphoedema/chronic oedema and how would this be best met?
Survey 1. Lymphoedema Practitioners

Scottish Lymphoedema Practitioners group

Lymphoedema Specialists in all 14 Health Boards

Practitioners

Lymphoedema Practitioners TOTAL 37

Survey 2. Generalists

National GMS lead

7/14 Local Medical Committees participated

432 practices

TOTAL GPs 116

Palliative Care Scotland

Palliative Care Doctors and TOTAL ‘others’ 15

National AHP lead

Lead AHPs – 9/14 Health Boards participated

Physiotherapists 116
Podiatrists 69
Occupational Th. 11
Dieticians 5
Pharmacists 3
Orthotists 2
Radiographer 1
TOTAL AHPs 207

Chief Nurse for Scotland

Lead Nurses – 8/14 Health Boards participated

Community Nurses 71
Hospital Nurses 29
Breast Care Nurses 10
Practice Nurses 8
Health Care Assistant 1
Other individual nurses 41
TOTAL Nurses 160

Total Generalists (non-lymphoedema trained Health Care Professionals) 498
Survey 2 Results – Generalists

• Responses n=498 (93% completion rate)

• 160 nurses, 125 doctors, 116 physiotherapists, 69 podiatrists, 11 occupational therapists, 5 dieticians, 3 pharmacists, 2 orthotists and various individual others

• Each profession was asked
  – identify their role regarding lymphoedema
  – their education need
  – how it could be met.
How well is your lymphoedema education need met?

Scale of 0 to 3
- 3 is completely met
- 2 is mostly met
- 1 is partially met
- 0 is not met at all

92.5% said they would benefit from further education on lymphoedema recognition and/or management.
Community Nurses  \( n=71 \) (of 160 nurses)

<table>
<thead>
<tr>
<th>Role regarding lymphoedema</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to other service/professional</td>
<td>80%</td>
</tr>
<tr>
<td>Identification of possible lymphoedema</td>
<td>76%</td>
</tr>
<tr>
<td>Application of bandages or other forms of compression</td>
<td>70%</td>
</tr>
<tr>
<td>Prevention advice to those at risk of lymphoedema</td>
<td>56%</td>
</tr>
<tr>
<td>Provision of lymphoedema management advice</td>
<td>47%</td>
</tr>
</tbody>
</table>
### Community Nurses education need

<table>
<thead>
<tr>
<th>Top 5 of 15+ possible education topics</th>
<th>C. Nurses n=71</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wound care/ leg ulcer care on lymphoedema patients</td>
<td>61%</td>
</tr>
<tr>
<td>Differential diagnosis of lymphoedema</td>
<td>59%</td>
</tr>
<tr>
<td>Awareness of current lymphoedema management techniques</td>
<td>58%</td>
</tr>
<tr>
<td>Advising skin care to reduce risk of cellulitis</td>
<td>52%</td>
</tr>
<tr>
<td>Assessment of patients with chronic oedema/lymphoedema</td>
<td>49%</td>
</tr>
</tbody>
</table>
Doctors – GPs  n=116

<table>
<thead>
<tr>
<th>Role regarding lymphoedema</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to other service/professional</td>
<td>95%</td>
</tr>
<tr>
<td>Diagnosing lymphoedema</td>
<td>83%</td>
</tr>
<tr>
<td>Identification of possible lymphoedema</td>
<td>77%</td>
</tr>
<tr>
<td>Prescription of compression garments</td>
<td>48%</td>
</tr>
<tr>
<td>Pharmaceutical management</td>
<td>43%</td>
</tr>
</tbody>
</table>
## Doctors (GPs) education need

<table>
<thead>
<tr>
<th>Top 5 of 15+ education topics</th>
<th>GPs n=116</th>
<th>LPs n=28</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness of current lymphoedema management techniques</td>
<td>81%</td>
<td>64%</td>
</tr>
<tr>
<td>Differential diagnosis of lymphoedema</td>
<td>75%</td>
<td>68%</td>
</tr>
<tr>
<td>Assessment of patients with chronic oedema/lymphoedema</td>
<td>69%</td>
<td>21%</td>
</tr>
<tr>
<td>Management of oedema in advanced disease</td>
<td>43%</td>
<td>21%</td>
</tr>
<tr>
<td>Advising skin care to reduce risk of cellulitis</td>
<td>39%</td>
<td>36%</td>
</tr>
</tbody>
</table>
Physiotherapists  

<table>
<thead>
<tr>
<th>Role regarding lymphoedema</th>
<th>n=116</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to other service/professional</td>
<td>84%</td>
</tr>
<tr>
<td>Identification of possible lymphoedema</td>
<td>56%</td>
</tr>
<tr>
<td>Prevention advice to those at risk of lymphoedema</td>
<td>36%</td>
</tr>
<tr>
<td>Provision of lymphoedema management advice</td>
<td>25%</td>
</tr>
<tr>
<td>Application of bandages or other forms of compression</td>
<td>9%</td>
</tr>
</tbody>
</table>
Physiotherapists education need

<table>
<thead>
<tr>
<th>Top 5 of 15+ education topics</th>
<th>Physiotherapists n=116</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise prescription for lymphoedema patients</td>
<td>73%</td>
</tr>
<tr>
<td>Awareness of current lymphoedema management techniques</td>
<td>64%</td>
</tr>
<tr>
<td>Differential diagnosis of lymphoedema</td>
<td>45%</td>
</tr>
<tr>
<td>Teaching self-massage Simple Lymphatic Drainage</td>
<td>42%</td>
</tr>
<tr>
<td>Assessment of patients with chronic oedema/lymphoedema</td>
<td>33%</td>
</tr>
</tbody>
</table>
### Podiatrists

<table>
<thead>
<tr>
<th>Role regarding lymphoedema</th>
<th>n=69</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to other service/professional</td>
<td>80%</td>
</tr>
<tr>
<td>Identification of possible lymphoedema</td>
<td>62%</td>
</tr>
<tr>
<td>Prevention advice to those at risk of lymphoedema</td>
<td>25%</td>
</tr>
<tr>
<td>Not my role</td>
<td>16%</td>
</tr>
<tr>
<td>Provision of lymphoedema management advice</td>
<td>15%</td>
</tr>
</tbody>
</table>
# Podiatrists education need

<table>
<thead>
<tr>
<th>Top 7 of 15+ possible education topics</th>
<th>Podiatrists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advising skin care to reduce risk of cellulitis</td>
<td>72%</td>
</tr>
<tr>
<td>Differential diagnosis of lymphoedema</td>
<td>68%</td>
</tr>
<tr>
<td>Awareness of current lymphoedema management techniques</td>
<td>53%</td>
</tr>
<tr>
<td>Identification of patients at risk of lymphoedema</td>
<td>53%</td>
</tr>
<tr>
<td>Assessment of patients with chronic oedema/lymphoedema</td>
<td>42%</td>
</tr>
<tr>
<td>Wound care/leg ulcer care</td>
<td>38%</td>
</tr>
<tr>
<td>Exercise prescription for lymphoedema patients</td>
<td>30%</td>
</tr>
</tbody>
</table>
Focus Groups

- **Focus group 1**  
  n=6

  4 Lymphoedema Practitioners  
  (nurses and physios, mix of experience levels, working in different contexts and different health boards)

  2 Podiatrists (community and acute, different health boards)

- **Focus group 2**  
  n=8

  GP,  
  District Nurse,  
  TVN (acute),  
  Cancer Nurse Consultant,  
  Gynaecology CNS,  
  Physio (general + learning disabilities),  
  Community Staff Nurse/lymphoedema practitioner trained,  
  Lymphoedema Specialist Nurse.

  (from different health boards)
Hidden problem

.........a lot of times these problems are hidden and they don’t talk about the problems they have with their legs. I have one patient in particular who has always worn long skirts, and she said ‘I’ve never shown the doctor my legs.

Group 2, Lymphoedema Specialist Nurse

I think one of the problems is the authorities don’t know the extent of the problem

Group 2, Tissue Viability Nurse
I have had patients who have started to develop lymphoedema, they have went to the GP and they have said that’s what it is, “you don’t have the cancer anymore so just get on with it. Just be grateful you don’t have the cancer”.

Group 1, Lymphoedema Specialist Physiotherapist
The meaning for a GP

Huge frustrations for us, because our district nurses won’t see people unless they are truly immobile, so unless you can prove they can’t get into a taxi, then they won’t visit at home. Our tissue viability nurses won’t go unless they have an ulcer, even though they have horrendous lymphoedema. The physiotherapist won’t visit or have anything to do with them, unless they have got breast cancer. So there are all these incredible and frankly pathetic barriers that stop you getting seen by someone. Our practice nurses won’t prescribe the dressings, because they say that they are not skilled in doing that, but neither am I frankly, they would know a lot more about that than me. 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, and that’s it; you can’t dodge and say, sorry your postcode is this, or that’s your neck, or we don’t do women. We have to deal with everything, … it frustrates me when people say ‘is it below the knee?’ I mean come on! We really need to look at how that works for patients, it’s really poor.

(81% of GPs wanted greater awareness of current lymphoedema management)
Lack of knowledge and cooperation across boundaries leading to feelings of incompetence or impotence

I feel at a loss, because I don’t know what to do really; I’m mopping it up a lot of the time, when they come in with their leaky legs and their cellulitis..........one of the frustrations I feel is, I’m fighting fires; I’m not actually dealing with anything

Group 2, Tissue Viability Nurse
Too big a problem for one speciality?

…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 [study days], just in case the referrals start coming through because we really can’t support a lymphoedema service added on to everything else.
Knowledge, confidence and a need to work across service boundaries

...the amount of exudates coming from any leg wounds that they have, I don’t know the way around that, but that definitely is a problem

[paid carers] have boundaries as well, what they will do, and what they won’t do. Some of them dress them, some don’t, some put [lymphoedema] stockings on, and others say ‘that’s not my job, I’m not trained to do that’. It’s just a nightmare getting care at home.

Group 2, Lymphoedema Specialist
The rewards

*She developed lymphoedema after her surgery, she just shut herself away, and she basically stopped walking as well..... to get her to a stage where she is now going out, taking her kids out and things like that, I think that’s the biggest step.*

Group 2,
Gynaecology Nurse speaking about a young woman in her care
Main recommendations

• On-line/intranet information linked into the resources currently used

• Incorporation of lymphoedema risk prevention and management advice into care pathways and information prescription routes to act as prompts and raise awareness.

• Addition of basic lymphoedema management information in all pre-registration/undergraduate training

A relatively small amount of extra understanding can help people use the skills & knowledge they already have; enhancing everyone’s role in lymphoedema management within their professional role.
References


Acknowledgements

• **Expert panel** – Dr A O’Neill (Research Supervisor), Dr C.Miller (Statistician), J.Harding & D.Murphy (Lymphoedema Specialists), E.Jones (Community Nurse Prescriber), Dr D.Linden (GP and Government advisor), A.Midgley (expert patient)

• **Steering group** – Y.Borthwick (Lymphoedema Specialist Physiotherapist/Teacher), E.Davis (Patient), M.Grundy (NHS Education for Scotland), K.Orr (Macmillan Cancer Support), Dr L.Paul (Reader in Rehabilitation), M.Sneddon (Head of Nursing, University of Glasgow). Dr B.Fitzpatrick (University Teacher & Researcher, University of Glasgow)

• **Survey distribution**: Scottish Lymphoedema Practitioner Network, Professional Leads Ann Cuthbert (Nursing), Hazel Dykes (AHPs), Mark Hazelwood (Palliative Care Scotland), Duncan Miller (Primary Care Doctors)

• **Funding** – NHS Education for Scotland, Macmillan Cancer Support, University of Glasgow

• **Administration** – E.Fisher, K.Doherty