

Chronic Oedema / Lymphoedema Service Mapping and Prevalence Project (Scotland)

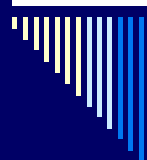
University of Glasgow

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Aims of Project

- To explore and map current chronic oedema/lymphoedema (COL) services in Scotland
- To undertake a prevalence study of lymphoedema and to provide an assessment of need



Definitions

- Lymphoedema – type of chronic oedema due to deficiency of the lymphatic system
 - Chronic oedema – prolonged swelling oedema, originating from a variety of causes, which, over time damages the lymphatic system, causing changes characteristic of lymphoedema.
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Phases of Project

- Phase 1: service mapping project
 - Phase 2: prevalence study
 - Phase 3; needs assessment
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Aims

- To report on the findings of the Service Mapping Project
 - To highlight related findings from an audit by Scottish Lymphoedema Practitioners
 - To discuss the challenges presented by the Prevalence Study and Needs Assessment (Glasgow) and some preliminary findings
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Service Mapping Project Objectives

- Identify key agencies involved in chronic oedema / lymphoedema management in relation to their geographical location within the NHS Board areas
 - Analyse current service models and referral patterns, describing how COL treatment and care is organised, delivered and funded
 - Explore experiences and views of COL practitioners in relation to current services and perceived need
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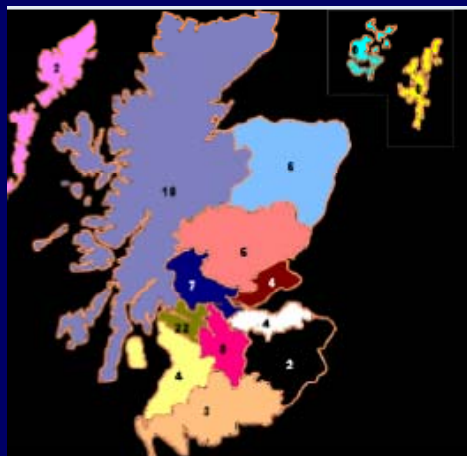
Mapping Project Methods

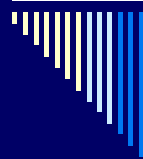
- Development of a database of practitioners and services
- Cross-sectional questionnaire survey (95)
- Audio-taped semi-structured interviews with individual practitioners (20)
- Specialist Practitioner focus group (1)

Respondents

- 61 Nurses (64%)
- 26 Physiotherapists (27%)
- 8 Other

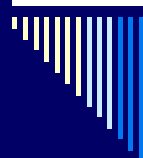
Number of Respondents in each Health Board





Practitioners Treating Various Types of Lymphoedema

- Secondary to breast cancer – 74%
- Secondary to other cancer – 35%
- Secondary to other condition – 32%
- Primary – 35%



Service Characteristics

- Fully funded – 73%
- No funding – 27%
- No protected time – 57%
- Waiting list for referrals – 20%
 - 1.5-20 weeks
- Waiting list for Treatment – 13%
 - 6-20 weeks



Practitioner Characteristics

- No formal training in lymphoedema – 23%
- Keyworker level training - 40%
- Individual modules - 21%
- Specialist skills (MLD) - 23%
- Diploma (comprehensive) – 9%
- Information needs identified - 79%
 - Treatment related - 30%
 - Preventing complications - 30%



Practitioner Information Needs

- None 21%
- Treatment options 30%
- How & where to refer 14%
- Where to go for help 18%
- How to assess patients 13%
- Skin care 18%
- Bandaging 22%
- Exercise 18%
- Preventing complications 29%
- Identifying patients at risk 8%



Practitioner Quotes

- I try to fit them in around my other working commitments.....If however we are carrying a vacancy or if we've got people off sick or anything like that, then my chronic oedema time drops...
- I think if we had more time and training or ongoing training, I think that would be good



More Quotes

- One of the problems that I have...are mainly from GPs who don't refer, who tell the patients it's nothing. Or tell them to put on a piece of tubigrip or raise their arm
- I sometimes feel we are a dumping ground (for difficult patients)



Garment Provision

- No restriction on supplies were identified
 - Ordering could be complicated with long waits for patients and additional appointments required
 - The addition of garments to the drug tariff had not relieved the problem for complicated patients
 - “It can sometimes take 4-5 weeks to get a garment for a patient by which time there can be change and the garment is no longer suitable”
 - “It is just the beaurocracy involved in ordering”
 - “we have no qualification. I don’t know where we stand...”
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Inequalities

- Those with breast cancer related lymphoedema perceived to be comparatively efficient and sufficient
 - There is restricted access to services for those with other types of chronic oedema with lymphatic deficiency / lymphoedema
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Challenges

- Reliance on services funded for cancer treatment or palliative care
- Practitioner COL role often not reflected in job profile; conflicting demands
- Cumbersome systems for ordering garments
- Practitioners not formal prescribers
- Lack of trained practitioners
- Poor knowledge of general health care professionals
- Support and ongoing education of practitioners



Scottish Lymphoedema Practitioner Network

- Audit of new patient referrals to 15 practitioners in 10 NHS Boards from April-June 2007
- 305 new patients with lymphoedema (241 in 2004):
 - 253 (83%) women
 - 52 (17%) men.
- Age: 163 (53%) >60 yrs: also 6 under 20 years



Issues raised

- Ratio of Cancer: Non-cancer was 73 : 27 (in Chronic Oedema Service this is 57 : 43).
- 41% of total had complicated lymphoedema requiring management by a specialist
- 13% of total had 'palliative'lymphoedema
- 81% had BMI >26



Prevalence Project and Needs Assessment

- Original objectives:
 - Estimate the numbers of people with COL, the type and severity of the condition in Scotland
 - Explore the experiences of people with COL in relation to current services and perceived need and describe the patient journey
- Planned methods:
 - Case ascertainment identifying patients via health professionals including
 - Respondents to Phase 1
 - Wide range of professionals via managers and established communication systems



Challenges

- Requirement to seek patient consent
- No direct contact with professionals or patients was possible
- Ethics Committee response
 - Definition of chronic oedema unsatisfactory and misleading
 - Seeking consent to provide data would put too much of a burden on health care professionals
 - Information on incapacitated adults must be excluded
 - Prevalence study findings could not be generalised
 - Letter to potential participants should not state that the study was important



Modifications and Consequences

- Definition of chronic oedema specified swelling does not subside on rest or elevation
- Use of CHI numbers for patient identification to avoid having to seek consent
 - Patients could not be consulted
 - Professionals either had to rely on memory or check through case records
- Omit term lymphoedema from documentation
- Prevalence study limited to Glasgow
- State explicitly that respondents must not contact patients
- Omit patient interviews as patients could not be identified – run as separate study with new approach to identifying subjects



Prevalence Study Outcome

- Disappointing response (732) – underestimation
 - 10% from acute services, 1% from community, remainder from specialist service
 - 0.84 per 1000 (Moffat study 1.33)
 - However same trends in terms of gender and age
 - Patients not receiving care in a specialist centre were less well controlled
 - Patients using diuretics were substantially less well controlled
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Prevalence continued

- Study suggests there will be 50,000 people in UK with lymphoedema, 20,000 of whom will be women with arm swelling.
 - Substantially lower than expected because:
 - Breast cancer incidence in Glasgow is lower
 - Incidence of lymphoedema in breast cancer patients in Glasgow is lower
 - Under ascertainment
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Needs Assessment

- Semi-structured interviews (17 women: 4 men)
- Breast cancer related lymphoedema – 6
- Other cancer related lymphoedema – 5
- Secondary to other causes – 4
- Primary lymphoedema – 6



Needs Assessment

- Delay in accessing services by non-cancer patients
- Strong feelings including despair, anger, isolation, helplessness
- Astounding lack of knowledge and sensitivity of health care professionals generally
- Getting to a specialist transformed their lives but was 'more by accident than design'
- Clothing and shoes are a major issue
 - Practically
 - Emotionally
 - Financially



Recommendations

- Ensure trusts have a service for non-cancer patients
- Consider contractual arrangement for existing services to take on additional patients
- Introduce clear referral criteria, well publicised
- Fully support a comprehensive awareness raising campaign
- All COL practitioners should have access to prescriber training
- Consider setting KPIs for Trusts, e.g. time to supply and fit a garment; allocation of funding
- Consider how patients with special clothing requirements might receive financial support