Accessing Lymphoedema Services in Fife

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Lymphoedema

• Failure in the lymphatic system →
• Chronic accumulation of fluid in the tissues
• Affects both upper and lower limbs
• Primary lymphoedema (no external cause) → predominantly lower limb
• Secondary lymphoedema (e.g. from treatments for breast cancer) → predominantly upper limb
• (Badger & Jeffs, 1997)
Lymphoedema Management

• Lymphoedema leads to reduced function and quality of life (biopsychosocial impacts)
• Evidence and expert consensus: lymphoedema management has positive impacts on limb volume
• Lymphoedema management requires specialist training and service provision
• (Badger & Jeffs, 1997)
Lymphoedema Services in Fife

Services in Fife (2003):
→ 1 part-time physiotherapist provides a specialist service (Dunfermline)
→ 2 clinicians provide lymphoedema management in a palliative care setting (Kirkcaldy)
→ 1 private practitioner (Glenrothes)

Concern that services were not adequate → Needs Assessment
Needs Assessment of Lymphoedema Services in Fife

• One of the questions addressed in the needs assessment:

  HOW ACCESSIBLE ARE LYMPHOEDEMA SERVICES?

• 2 sources of information:
  → Referrers
  → Providers
Methods

1.) Referrers:
• short targeted telephone survey → awareness of lymphoedema and referral practices; descriptive analysis
• stratified random sample of 44 general practitioners (8-10 from each LHCC); GPs from 62% of listed practices participated

2.) Providers:
• qualitative interviews with providers from 3 services → experiences of access for clients;
• thematic analysis within a postpositivist framework
Results: Triangulated Findings
1.) Poor likelihood of referral for investigations and management

- Lack of awareness of lymphoedema
  - 36% of referers had diagnosed no cases; 16% had no previous experience at all;
- Low credibility given to the potential for management
  - 23% unsure/felt there was little a GP could do; providers: “they’re not sure how to deal with it”
- Lack of awareness of lymphoedema services
  - only 11% would refer directly to specialist services
- All leading to poor likelihood of referral
  - 30% described delaying referral, e.g. until symptoms deteriorate
2.) Limited geographical access

- Impact of geographical proximity to services → greater awareness and likelihood of referral
  - 4 out of 5 GPs who would refer to specialist services are in close proximity to those services
- Impact of geographical distance and centralised services → reliance on private transportation
  - Provider comment: “North-East Fife is very out on a limb”; the independent practitioner manages clients who travel long distances
Conclusions

• Access to lymphoedema services in Fife is limited by:
  → poor referral practices
  → centralisation of services

• Recommendations:
  → evaluate different models of service delivery
  → explore methods of promoting specialist services