

A needs assessment of lymphoedema services in Fife and resulting recommendations

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Lymphoedema is a chronic condition that leads to reduced quality of life through its negative impacts on physical, psychological, and social aspects of health. Limb swelling leads to discomfort and pain, reduced movement and function, and acute inflammatory episodes. Individuals experience altered body image and self-esteem impacting on social interaction. There is evidence that specialist management of the condition leads to improved quality of life. Concern regarding the adequacy of lymphoedema services led to the commissioning of a needs assessment by the Core Cancer Review Group in Fife, Scotland. The needs assessment used a variety of methods. Current services were located through consultation of known providers and databases. Existing databases were analysed to find out the number of people requiring the service: hospital admissions and diagnoses were analysed alongside a survey of primary practices in Fife. Access to existing services was explored through a telephone survey of referrers ($n = 44$), and qualitative interviews with five service providers and five clients. At the time of the study, non-palliative National Health Service (NHS) provision consisted of one part-time clinician; the service provided was under pressure from rapidly increasing referrals. However, consensus from referrers, providers, and clients indicated that there were obstacles to achieving diagnosis and referral, especially for those with non-cancer-related lymphoedema. This was primarily due to poor referrer awareness of the condition, its management, and existing services, for example, only seven per cent of those surveyed would refer to existing specialist services. Delayed referral is a significant issue, as prompt intervention leads to more positive treatment outcomes. As a result of the needs assessment, recommendations were made to increase staffing levels, promote awareness of the condition and related services, and improve geographical and multidisciplinary coordination of the service.

Key words: lymphoedema; needs assessment

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Introduction

This article summarizes the methods and findings of a needs assessment, forming the rationale for recommendations to develop lymphoedema services in

Fife. Funding for the needs assessment was generated through communication of user and provider concerns to the CCRG in Fife, who commissioned the development of a full report between January and November 2003 (Bulley, 2003). This project first aimed to generate a case for lymphoedema as a health-related need with potential to benefit from health care. It proceeded by investigating the current state of service provision to make recommendations for service development. This article focuses on the latter component of the needs assessment.

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Lymphoedema is a chronic accumulation of fluid in the tissues where the lymphatic system cannot provide adequate circulation. Where it develops as a result of damage caused to the lymphatic system lymphoedema is classified as secondary. Primary lymphoedema occurs with no apparent external cause (BLS, 2001). In developed countries the disorder frequently develops through damage to the lymphatics during surgical or radiotherapeutic treatments of cancer, particularly that of the breast (Tibbs *et al.*, 1997). As oedema accumulates, tissue changes result in the development of fibrotic, thickened skin. This can lead to considerable discomfort, and in some cases, severe pain (Pain and Purushotham, 2000; BLS, 2001; Board and Harlow, 2002). Individuals with lymphoedema usually experience reduced quality of life as a result of impaired function, altered body image, and impacts on social and sexual confidence (Tobin *et al.*, 1993; Woods, 1993; Hare, 2000; Pain and Purushotham, 2000).

Although lymphoedema is a chronic condition, there is evidence to support its management through a combination of specialized massage, compression, exercise, and skin care, designated 'Complex Decongestive Therapy' (CDT). Advice and lifestyle adjustments are very important to prevent acute inflammatory episodes and further deterioration (Badger and Jeffs, 1997). There is consensus in the literature regarding best practice. Several sets of guidelines or consensus documents have been produced in the UK, US, and Canada (Kirshbaum, 1996; Oncology Section of the American Physical Therapy Association, 2000; Harris *et al.*, 2001). CDT was also recommended in a recent clinical guideline for the management of breast cancer (SIGN, 1998).

Studies of the effect of different components of CDT have been synthesized in two systematic reviews (Megens and Harris, 1998; Karki *et al.*, 2001). Comparison of studies was found to be limited by lack of standardization in therapy administration and outcome measurement, as well as issues relating to study design. However, all studies found reduced swelling as a result of therapeutic intervention. More recently two randomized-controlled trials were conducted by Didem *et al.* (2005) and McNeely *et al.* (2004). Again, significant reductions in swelling were found as a result of specialist treatment, although research has neglected outcomes such as function or quality of life.

Despite the small quantity of rigorous research, the evidence supports the need of this group for disease-specific health care provision. However, postgraduate training is required for professionals who wish to develop skills in lymphoedema management, which is not claimed as a specific role of any single health profession. The Lymphoedema Support Network advises individuals with lymphoedema that management is usually carried out by nurses and physiotherapists with specialist training (Hardy and Mortimer, 2004). There is a lack of expertise in the UK, which compounds low prioritization for funding and leads to frequent inequalities in provision.

Specialist lymphoedema management is provided in Fife. However, concerns were expressed by lymphoedema service providers in relation to the lack of equitable and adequate service provision for their clients over a large geographical area. Clinical governance requires that patients are central drivers of change, with service providers acting as key agents in the change process (Scottish Executive, 2003). It is therefore appropriate that voiced concerns were heard by potential funders who questioned the extent of the need within the area, and commissioned a focused needs assessment. This aimed to 'explore identified problem areas in depth to inform planning of service provision' (Scottish Needs Assessment Program, 1998). The needs assessment was carried out within an epidemiological approach, which involves the investigation of incidence and prevalence of individuals who can benefit from effective health care and access to services with potential to meet that need (NHS Management Executive, 1991b in Porteus, 1996; Stevens *et al.*, 2003).

This article outlines the methods used to investigate provision and adequacy of current services, as well as ease of access. The specific questions addressed are listed below, after which methods of investigation are outlined. Data collected were used to discuss the extent to which service provision was meeting identified need, and to develop recommendations for service development.

Needs assessment questions:

- 1) What services are currently provided?
- 2) How many people require the service (incidence and prevalence)?
- 3) How easily is the service accessed?

Methodology

The epidemiological approach to needs assessment places particular emphasis on incidence and prevalence to establish population need for a service. Incidence is the rate of occurrence of a disease in relation to the population size, over a specified period of time. Prevalence is the number of people with the disease or disorder at a single point in time (Logan, 1995), particularly relevant when investigating a chronic condition such as lymphoedema. However, both incidence and prevalence are extremely difficult to establish in this group, as their estimation relies the recording of a diagnosis in a retrievable format, which is often not carried out. Therefore it was important to triangulate information from different sources to infer the level of need in the area.

Several methods were used to determine current service provision, numbers of individuals requiring the service, and ease of access. These methods include the location and analysis of existing databases, a mail survey of primary practices, a telephone survey of referrers, and face-to-face interviews with service users and providers. These are described in turn. Referrers were general practitioners (GPs), providers included any specialist lymphoedema practitioner working within the catchment area, and users were individuals currently being managed within the specialist NHS service. For ethical and logistical reasons it was not possible to talk with individuals who were not diagnosed and under the management of a consultant. However, retrospective experiences prior to diagnosis and referral were explored. Ethical approval was granted by the Fife NHS Board Local Research Ethics Committee. Questionnaires and topic guides were reviewed and approved by a member of the Core Cancer Review Group.

Location and analysis of existing databases

Lymphoedema services in Fife were located through discussion with known lymphoedema service providers, referrers, and consultation of Internet databases.

It was important to increase knowledge of the numbers of actual and potential service users. Actual service users were established by descriptively analysing operation statistics collected by the lymphoedema service since its inception in

1996. Potential service users were explored by requesting data from Fife NHS Board Information Services, who summarized numbers of hospital admissions with a diagnosis of lymphoedema, by cancer type and cause, during the previous five years (Fife NHS Board Information Services, 2003).

Mail survey of primary practices

In order to further understand the numbers of potential service users, a mail survey was sent to all primary practices that were both willing to participate, and able to access information electronically. This requested specific details relating to the numbers of individuals being managed within the primary practice with diagnoses of lymphoedema secondary to cancer and lymphoedema of no known cause.

Telephone survey of referrers: GPs

There were several aspects of the study questions which were best addressed through direct communication with referrers to lymphoedema services. This ensured that all available services were accounted for and enabled a brief exploration of the experiences of referrers in relation to lymphoedema and referral for management. A short telephone survey of referrers was selected as a pragmatic tool for obtaining a rapid overview of opinions and practices. This was very important for a group of professionals who experience many conflicting pressures and it was anticipated that a more time-consuming mail-administered survey would lead to non-response. A purposive sample of 10 GPs was sought from each of the five Local Health Care Cooperatives (LHCC) in Fife, aiming for a total of 50 responses. Sampling continued until 10 responses were obtained or the number of contacts was exhausted within each LHCC. Six questions were strictly focused. Direction of referral was established by asking which services GPs would refer patients to. The likelihood of referral was explored by asking about the stage at which referral would be likely to occur and by investigating views regarding the needs of lymphoedema patients. Access to services was also explored by asking about whether or not these needs were being met.

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Face-to-face interviews with service users and providers

It was important to increase understanding of the adequacy of service provision, including different aspects of access to the service, before and after referral. The experiences of both service users and providers were relevant to this exploration. Qualitative interviews were carried out within the post-positivist philosophical tradition (Secker *et al.*, 1995). Interviews were carried out at four service locations, in quiet, private locations; two lymphoedema practitioners were involved in one interview (Table 1). Semi-structured interviews focused on the study aims, while allowing unexpected issues to be raised. Tables 3 and 4 summarize the topics explored through open and probing interview questions (Grbich, 1999). Transcribed data were analysed and participants reviewed and approved the final report before submission to ensure that they were comfortable with the public representation of their views.

A small, purposive sample of five clients of the Queen Margaret Hospital lymphoedema service was sought, to include experiences of primary and

secondary lymphoedema affecting upper and lower limbs (Table 3). Seven clients were sent the information sheet by their physiotherapist, allowing for non-response. Qualitative data is rich and time-consuming to collect, process, and analyse. A sample of five was considered sufficient to provide a representation of different experiences and views while not claiming to reach a theoretical data saturation point (Grbich, 1999).

Where willing to participate, individuals contacted the researcher. They were given an opportunity to inquire further, and they were assured of their right to withdraw at any time. Interviews were carried out individually, in a familiar, comfortable, and private location. Consent was provided in the presence of a witness (another health professional) as required by the ethics committee.

The interviews were transcribed and analysed for broad themes relating to the study questions, although flexibility allowed unexpected emergent themes. Supporting data are provided in the form of quotations where appropriate, and further information can be provided on request. Data obtained from service providers and clients were triangulated

Table 1 Summary of lymphoedema services in Fife in 2003

Service	Location	Staffing level	Referral source	Clientele
1) Specialist NHS Lymphoedema Service	South Fife + one to two days/month in Kirkcaldy	0.5 FTE Senior I Physiotherapist and 0.1 FTE Senior II Physiotherapist	Consultant referral is necessary for differential diagnosis and access to surgical appliances; referrals from: Queen Margaret Hospital Breast Service, general surgeons, oncology and vascular consultants	Primary and secondary lymphoedema
2) NHS palliative care service	South Fife	1 Senior I Physiotherapist 1 Nurse	Palliative care referrals, from oncologists, GPs, chest physicians, and clinical nurse specialists	Lymphoedema care provided to clients of the palliative care service as part of a package of care
3) Independent practitioner	Mid-Fife	1 Independent practitioner trained in lymphoedema therapy	Self-referral; some GPs make clients aware of this service	Primary and secondary lymphoedema
4) NHS District Nurse	South Fife	1 District Nurse	No referrals for lymphoedema treatment; assistance provided as part of shared care	Non-specialist assistance provided to the palliative care service in home care of individual patients

to achieve greater depth of understanding and greater trustworthiness of interpretation (Secker *et al.*, 1995).

Results

Findings are presented in relation to current service provision and use, demand for services, and access.

Current service provision and use

Lymphoedema services in Fife are summarized in Table 1. At the time of the study, the specialist NHS service represented the only public funded provision for individuals with all forms of lymphoedema. The service was located in the more densely populated southern area of Fife. The independent practitioner received patients with all forms of lymphoedema and was located further north. Lastly, the NHS Hospice provides lymphoedema management in the palliative care service.

Use of the only specialist NHS lymphoedema service was explored by analysis of their operation statistics database. Figure 1 illustrates the gradually accelerating patient load over a five-year period.

Potential service users: estimation of incidence and prevalence

In order to triangulate information relating to incidence and prevalence of lymphoedema in Fife, secondary data were requested from the NHS Board and a survey of primary practices was conducted. Fife-wide statistics were provided by the Fife NHS Board in relation to numbers of lymphoedema diagnoses and hospital admissions with a diagnosis of lymphoedema by cause, between 1997 and 2002. Figures 2 and 3 illustrate this data, which indicate a mean incidence of 17 cases of lymphoedema per year diagnosed in a hospital setting, and 38 admissions related to lymphoedema per year (Fife NHS Board Information Services, 2003).

The survey response from primary practices was poor; 42 out of 58 primary practices did not respond. Data were provided by 11 practices; 5 were subjective estimates, 4 were electronic data retrievals, and 2 did not state their data source. As a result of this response, and the likely existence of undiagnosed cases, the accuracy of data analysis is very limited. Data are summarized in Table 2. The third listed LHCC provided 5 estimates, while the other four LHCCs provided 1 or 2 estimates each. For this reason, data from the third LHCC were extrapolated using general population numbers provided by the Primary Care Trust in 2003. A highly tentative

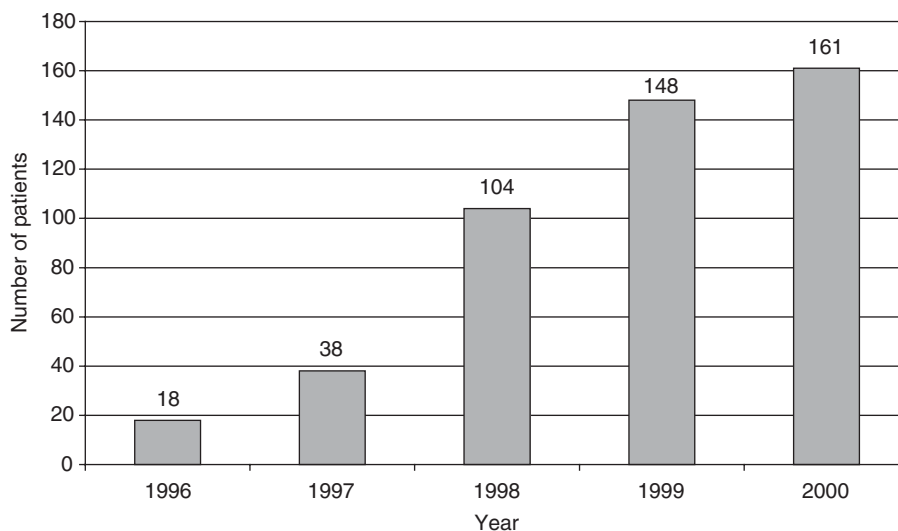


Figure 1 Specialist NHS lymphoedema service: total patient load from January 1996 until December 2000 (*Note: the year 2001 is excluded as the data are incomplete*)

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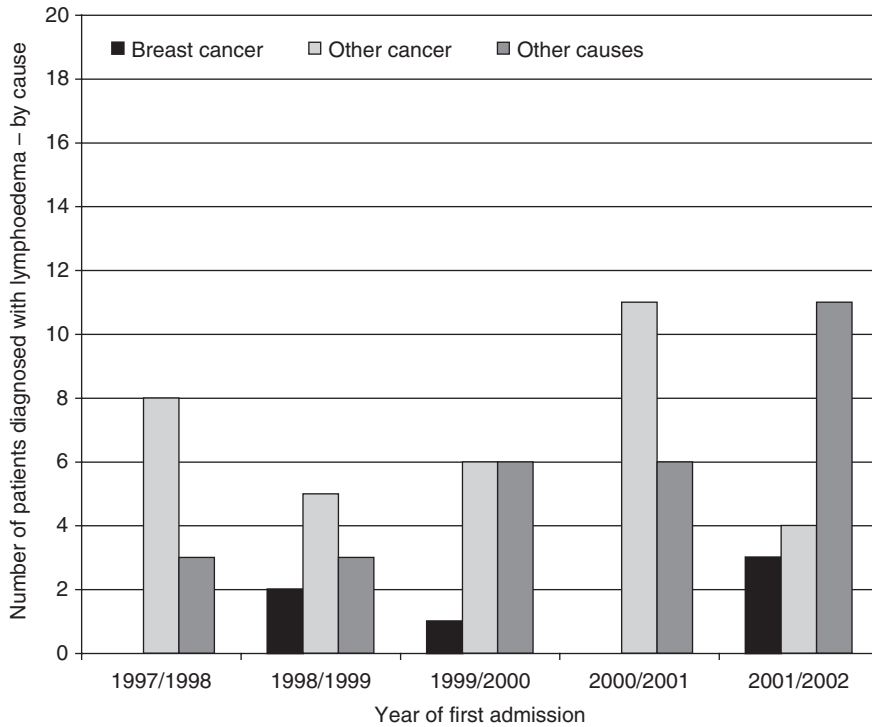


Figure 2 Number of patients diagnosed with lymphoedema of different causes between the years 1997 and 2002

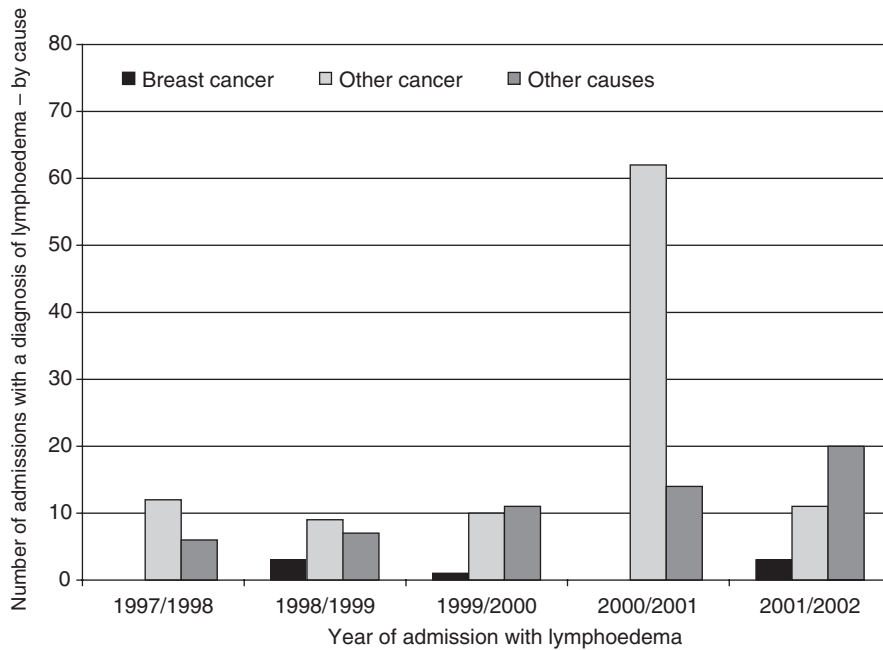


Figure 3 Number of admissions with a diagnosis of lymphoedema of different causes between the years 1997 and 2002

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Table 2 Summary of the total estimated prevalence of lymphoedema in each LHCC in Fife

LHCC	Total LHCC population	Participating practices		Number of lymphoedema cases estimated by participating practices		Estimated prevalence of primary lymphoedema		Estimated prevalence of secondary lymphoedema		Estimated total prevalence of lymphoedema in life	
		Number	Total population	Primary	Secondary	Number	(%)	Number	(%)	Number	(%)
1	62 959	2	16 545	4	6	15.22	0.02	22.83	0.04	38.05	0.06
2	51 120	1	5953	1	1	8.59	0.01	8.59	0.02	17.18	0.03
3	74 015	5	23 744	5	11	15.59	0.02	34.29	0.05	49.88	0.07
4	73 354	1	4825	0	2	30.41	0.04	0.00	0.00	30.41	0.04
5	74 366	2	5950	3	1	37.49	0.05	12.50	0.02	49.99	0.07
Total	335 814	11	57 017	13	21	107.30	0.03	78.21	0.02	185.51	0.06

prevalence estimate was provided as a result: approximately 0.55/1000, or 71 individuals with primary lymphoedema (0.021% of the population of Fife) and 156 with secondary lymphoedema (0.046%).

Access to specialist lymphoedema services

Three main sources of information were analysed in relation to access: a telephone survey of referrers, and interviews with lymphoedema service providers and users. Findings from the survey will be described, while emergent themes from interview transcripts are summarized in Tables 3 and 4. There was a reasonable response to the telephone interviews of referrers; 44 responses were obtained out of a possible 50, with at least 8 from each LHCC. Several issues came to light, including a lack of awareness of lymphoedema, of its management, and of available services.

Responses to the referrer survey indicated that 37 of the 44 respondents had some experience of lymphoedema. Over a quarter of the GPs surveyed (14) described patient-driven referrals and 16 would carry out immediate or early referral. However, 11 respondents would only refer to lymphoedema services if they could not manage it in primary care, or if they were informed of better management elsewhere. One respondent felt that she and her patients were not aware of current information regarding management options and their efficacy. Five GPs expressed resignation that there is little that they or anyone else can do. To quote one respondent, individuals with lymphoedema 'just have to live with it'.

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Only 5 of the surveyed referrers indicated that they would refer to a specific lymphoedema service. Of these, 4 worked in close geographical proximity to these services, 10 others were unaware of services or the referral processes. One practitioner explained that there are probably a lot of people who do not receive treatment as a result; 14 GPs would refer patients to the Breast Clinic or their Oncologist, while 18 practitioners would refer to their local physiotherapist or district nurse, despite their lack of experience and confidence in managing the condition.

It was interesting to note that several GPs had experienced greater difficulties in accessing treatment for primary lymphoedema compared with secondary, which is frequently related to cancer. This was confirmed in responses from providers. Although the palliative care service experienced few barriers to referral, the specialist NHS service had experienced a widely varying speed of referral. In some cases this led to delays of months, particularly for individuals with primary lymphoedema. This emerged in themes labelled as 'time to referral' and 'barriers', defined further in Table 3. To illustrate these themes, one lymphoedema provider explained:

'the knowledge of treatment that's available is quite limited, so if you have primary lymphoedema, your GP will probably not know where to refer you'.

This triangulated with themes generated from transcripts of interviews with service users (Table 4), particularly those labelled 'practitioner

Table 3 Interviews with lymphoedema service providers: topic guide questions and emergent themes regarding access to lymphoedema services and quality of service provision

Interview participants

- Specialist NHS Lymphoedema Service: part-time physiotherapist
- NHS Hospice palliative care service: full-time physiotherapist, full-time nurse
- District Nurse who had supplemented the care provided by the NHS Hospice on two occasions
- Independent practitioner trained in lymphoedema management

Topics of interview questions^a

- Client base – numbers of: new clients; review clients; clients with primary and secondary lymphoedema
- Source of referrals and funding
- Service accessibility; time periods between: clients seeking help and being referred for management; between referral and assessment
- Management strategies used, guidelines and policies followed, frequency and duration of treatment sessions

Emergent themes

- Numbers
- Lymphoedema type
- Source
- Frequency
- Duration
- Assessment
- Treatment
- Time to referral
- Barriers
- Time to treatment
- Quality
- Knowledge
- Coordination
- Inequality of care
- Access
- Prevention

Theme descriptions

- The numbers of individuals using lymphoedema services
- The types of lymphoedema suffered by individuals starting to use lymphoedema services
- Source of referral of individuals to lymphoedema services
- The frequency of treatment sessions during the intensive and maintenance phases of management
- The duration of treatment sessions during the intensive and maintenance phases of management
- The assessment component of the intensive phase of management
- The treatment component of the intensive and maintenance phases of management
- The time taken between individuals seeking help and being referred to lymphoedema services
- Factors that get in the way of individuals being referred to lymphoedema services
- The time taken between individuals being referred to lymphoedema services and being assessed
- Issues relating to the quality of lymphoedema services
- Knowledge required for the management of lymphoedema
- Coordination of services required by individuals with lymphoedema
- National and local inequalities of service provision for individuals with lymphoedema
- Geographical access to services for individuals with lymphoedema
- Use of service structures to implement measures aiming to prevent the development of lymphoedema

^a Topic guide was reviewed and approved by a member of the Core Cancer Review Group.

knowledge or understanding’, ‘access to investigations’, ‘time elapsing before referral’, and ‘barriers to referral’. The theme ‘practitioner knowledge or understanding’ is exemplified in two comments:

‘they were all conflicting [...] about it, as if it wasn’t important’, while another felt: ‘people weren’t really listening to me, the surgeons were more interested in my wound and they weren’t really interested in my arm’.

The lack of referrer awareness raised the importance of preventive advice. It was notable that of the five clients interviewed, those with previous knowledge of lymphoedema sought help sooner

and more persistently, which was necessary to obtain diagnosis and referral.

Once referred, some individuals experienced further barriers to receiving treatment, such as poor geographical access, especially during the early, intensive phase of management (Table 3: ‘Access’). The independent practitioner explained:

‘it’s a big county ... there’s virtually no public transport ... and that side of Fife to this side of Fife is a four-hour trip’.

Two service users confirmed this, explaining that they rely on independent transport. Unfortunately, growing pressure on the current service has prohibited home visits (Table 4: ‘Access to treatment’).

Table 4 Interviews with lymphoedema service clients: topic guide questions and emergent themes regarding access to lymphoedema services and quality of service provision*Interview participants*

- Five female clients of specialist NHS lymphoedema service – selected for their accessibility within an existing structure
- Characteristics: Two had unilateral primary lymphoedema of the lower limb of five years and eight months duration; three had unilateral secondary lymphoedema of the upper limb following breast cancer, of approximately six months, eighteen months, and twelve years duration

Topics of interview questions^a

- Prior awareness of lymphoedema and experiences of seeking and locating appropriate assistance
- Experiences of lymphoedema management – strategies, duration, accessibility

Emergent themes

- Direction of help sought
- Practitioner knowledge/ understanding
- Access to investigations

Theme descriptions

- The individual or agency from which help was sought in relation to lymphoedema, prior to diagnosis
- The knowledge or understanding perceived to be held by the individual or agency from which help was sought
- The amount of assistance given in relation to referral for investigation of symptoms relating to lymphoedema, by the individual or agency from which help was sought
- The time that elapsed before an individual was referred for lymphoedema management
- The directions in which an individual was referred for lymphoedema management
- Factors that presented a barrier to an individual being referred for lymphoedema management
- Experiences of accessing treatment for symptoms relating to lymphoedema once an individual was been diagnosed and referred for management

^a Topic guide was reviewed and approved by a member of the Core Cancer Review Group.

In general, service providers indicated that the period between referral and first assessment by a service appears to be fairly short, from a few days to two weeks. However, the increased patient load of the specialist NHS service has raised a potential future barrier to services, emerging within the theme ‘Inequality of care’ (Table 3). At the time of this needs assessment, a prioritization exercise was being considered, which could place individuals with non-cancer-related lymphoedema on a waiting list. The independent practitioner felt that the difficulties experienced by this group were inappropriate:

‘it’s that disparity again, some do get and some don’t get, and that doesn’t seem right ... they have to fight to get care’.

Discussion

Triangulation of different data sources indicates that at the time of the study there were few specialist services available to individuals with either

cancer-related or non-cancer-related lymphoedema. Highly tentative prevalence estimates suggested that need exceeded supply, but other access issues appeared to pose a greater initial problem. Barriers included low awareness of the condition and of specialist services, as well as the concentration of service provision in the south of a large geographical area.

Triangulation of quantitative and qualitative data regarding use of lymphoedema services provides evidence of unmet need. As referrals had steadily increased over the period since its inception, the specialist NHS service was experiencing growing pressure. However, it is hard to estimate the full extent of unmet need, owing to difficulties in estimating prevalence of the disorder.

Firstly, although hospital admissions data suggest an annual increase of 17 diagnosed cases of lymphoedema, statistics are limited by their reliance on admission to hospital, which is not always necessary with a chronic disorder. Casley-Smith and Casley-Smith (1997) state that numbers of cases reported by health statistics are actually far fewer than the real numbers, as so few individuals

enter hospital. Owing to inadequate records, the real number is almost impossible to define. An additional problem is that many medical professionals do not give credence to its existence, leading to misdiagnosis. Both of these problems were evident in the needs assessment findings, with a lack of electronic databases in primary practices, and high level of non-response to the questionnaire relating to prevalence. These factors must be considered when considering lymphoedema prevalence estimation in Fife.

Data obtained during this needs assessment were extrapolated to provide a tentative estimate of approximately 0.55/1000. Previous studies support the likelihood that this underestimates the true prevalence value. A study by Moffatt *et al.* (2003) surveyed the catchment area of London to identify individuals with chronic oedema. They crudely estimated prevalence at 1.33/1000. However, this also relied on recognition and diagnosis. A recent study of incidence after breast cancer treatment found that 21% developed lymphoedema within three years (Clark *et al.*, 2005). Considering the increasing numbers of women surviving breast cancer, the prevalence of lymphoedema within the population is likely to grow.

Although incidence and prevalence estimates were flawed, they did suggest a trend of increasing incidence and prevalence of diagnosed lymphoedema, possibly related to increased awareness among referrers. It is impossible to compare the tentative estimate of lymphoedema prevalence in Fife with other studies, as these have focused solely on breast cancer-related lymphoedema. Further studies will be of great value, at a time when all primary practices have electronic databases, and there is greater assurance of diagnosis.

However, evidence of unmet need within Fife also related to access. Triangulation of data from referrers, providers, and users indicated that diagnosis and referral were frequently delayed owing to a lack of awareness of the condition and its potential for management. The likelihood of referrers being aware of available services appeared to decrease with geographical distance from the service. Previous qualitative studies involving both interviews and focus groups have also uncovered delays to referral resulting from a lack of awareness. Individuals had often been informed that nothing could be done, or told not to worry (Hare, 2000; Norman *et al.*, 2001).

It appeared that service provision was sufficient for individuals with cancer-related lymphoedema, with comparatively fewer barriers to diagnosis and referral, although this was not guaranteed. Clients with both types of lymphoedema described having to be persistent in requesting help, which depended on prior knowledge of lymphoedema. In contrast, individuals with primary lymphoedema were likely to experience lengthy delays owing to the lack of awareness of referrers, and a lack of coordination of investigation and diagnosis. This issue was raised by Sitzia and colleagues, who surveyed 27 lymphoedema management centres in the UK. They found that fewer than 20% of this population had primary lymphoedema, but they were more likely to have a high level of swelling in more than one limb. Substantial management problems were stated to be compounded through late referral (Sitzia *et al.*, 1998).

Once an individual had been referred to a lymphoedema management service, their first assessment was generally prompt, although pressure on the specialist NHS lymphoedema services was leading to the consideration of a waiting list system. However, there were concerns from both providers and users about the centralization of services, making geographical access to management a problem for some. It is important to note that early referral and treatment for lymphoedema management is likely to be more cost-effective, as there is less swelling and a greater likelihood of minimizing the functional effects of the disorder. This will reduce the burden on social services by preventing the degree of psychosocial and functional impact on individuals, and their social and economic associated costs (Mirolo *et al.*, 1995). The issues raised by the needs assessment were used to provide a rationale for recommendations for service development.

Recommendations for the development of service provision

Recommendations are summarized alongside their rationale in Table 5, and were designed in a three-stage development plan to allow structured development as resources become available. Probable underestimates of prevalence provided a basis for a recommendation to increase staff levels; they indicated that a lymphoedema service in Fife need not be very extensive in size, but requires

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Table 5 Recommendations: summary of a three-stage development plan for lymphoedema service development

Issues identified through needs assessment	Recommendations: Stages 1–3
<p><i>Stage 1</i></p> <ul style="list-style-type: none"> ● Tentative prevalence estimates amounted to approximately 230 ● Preventive activities are important to facilitate individuals in taking rapid and persistent action in seeking help ● Pressure on the specialist NHS lymphoedema service has led to discussion regarding a prioritization exercise ● Delays in referral were experienced as a result of poor awareness of the disorder and of the available services 	<ul style="list-style-type: none"> ● Increase staffing from 0.6 FTE physiotherapists to one full-time Physiotherapist specializing in lymphoedema management; roles to include: <ul style="list-style-type: none"> – preventive activities – initial assessments, intensive, and maintenance therapy – awareness raising and education in the acute setting
<p><i>Stage 2</i></p> <ul style="list-style-type: none"> ● There is increasing pressure on the Queen Margaret Hospital lymphoedema service ● There is evidence of geographical inequalities in access to services: physical access and differences in referrers' awareness of service availability and their referral processes ● Greater coordination of services in the acute setting would improve the speed of referral to lymphoedema services ● Ongoing audit and revision of staffing requirements is crucial, as estimates of prevalence and the required staffing are tentative and are likely to increase with increased awareness of services 	<ul style="list-style-type: none"> ● Increase staffing to include a full-time nurse or physiotherapist, trained to keyworker level; roles to include: <ul style="list-style-type: none"> – roving clinics in primary care settings throughout Fife – initial assessments and maintenance therapy – awareness raising and education in primary care ● Modify the duties of the full-time specialist <ul style="list-style-type: none"> – intensive therapy in the acute hospitals – development of referral criteria and service boundaries – preventive activities – awareness raising and education in the acute setting – development of an audit and monitoring system
<p><i>Stage 3</i></p> <ul style="list-style-type: none"> ● There is evidence of geographical inequalities in access to services ● Increased awareness of lymphoedema management among other health professionals would allow their supplementation of activities provided by lymphoedema services 	<ul style="list-style-type: none"> ● Incorporate the capacity for an inpatient intensive phase for patients who live too far away for frequent travel ● Develop patient support groups ● Aim to provide keyworker home visits where required ● Seek funding for increased education of health professionals

good coordination. Increased awareness of services will also lead to increased referral rates, therefore ongoing monitoring and revision of staffing requirements is crucial.

An important role for the service to develop relates to the promotion of awareness of the condition throughout the primary and acute sectors, to ensure prompt diagnosis and referral. Education of nurses and allied health professionals would enable them to facilitate patients where possible, and would provide a point for consultation.

A further development suggestion relates to the problems of geographical access. It is preferable that initial assessments and complex treatments are conducted by a more highly trained lymphoedema

practitioner in the central location. However, maintenance treatments can be conducted by a less trained 'keyworker' within each LHCC as required. This would also contribute to succession planning, ensuring ongoing development of appropriate expertise.

Conclusions

This needs assessment has identified gaps in service organization and provision that impact on the likelihood of individuals receiving management for their chronic condition. Recommendations have been made for service development to ensure that

individuals with lymphoedema are diagnosed and referred to specialist services and able to access the management they need. Further work is required in the area, including well-designed studies of incidence and prevalence, more rigorous studies of components of lymphoedema management, and systematic reviews of the evidence. There are projects underway to map services in different areas, and this should lead to the evaluation of different models of service delivery.

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References

- Badger, C.** and **Jeffs, E.** 1997: *Macmillan lymphoedema project*. London: Macmillan Cancer Relief.
- Board, J.** and **Harlow, W.** 2002: Lymphoedema 2: classification, signs, symptoms and diagnosis. *British Journal of Nursing* 11, 389–95.
- British Lymphology Society (BLS).** 2001: *Chronic oedema population and needs*. Caterham: BLS.
- Bulley, C.** 2003: Needs assessment of lymphoedema services in Fife. Unpublished report for the Core Cancer Review Group in Fife.
- Casley-Smith, J.** and **Casley-Smith, J.R.** 1997: *Modern treatment for lymphoedema*. Adelaide: The Lymphoedema Association of Australia Inc.
- Clark, B., Sitzia, J.** and **Harlow, W.** 2005: Incidence and risk of arm oedema following treatment for breast cancer: a three-year follow-up study. *Queensland Journal of Medicine* 98, 343–48.
- Didem, K., Ufuk, Y., Serdar, S.** and **Sumre, A.** 2005: The comparison of two different physiotherapy methods in treatment of lymphedema after breast surgery. *Breast Cancer Research and Treatment* 93, 49–54.
- Fife NHS Board Information Services.** 2003: Statistics relating to diagnoses of lymphoedema and related hospital admissions in Fife between 1997 and 2002, SID03/JC/021.
- Grbich, C.** 1999: *Qualitative research in health: an introduction*. London: Sage Publications Ltd.
- Hardy, D.** and **Mortimer, P.** 2004: *What is lymphoedema?* [online] Lymphoedema Support Network. Retrieved 3 March 2005 from, <http://www.lymphoedema.org/lsn/lsn010.htm#TOP>
- Hare, M.** 2000: The lived experience of breast-related lymphoedema. *Nursing Standard* 15, 35–39.
- Harris, S., Hugli, M., Olivetto, I.** and **Levine, M.** 2001: Clinical practice guidelines for the care and treatment of breast cancer, 11: lymphedema. *Canadian Medical Association Journal* 164 (2), 191–99.
- Karki, A., Simonen, R., Malkia, E.** and **Selfe, J.** 2001: Efficacy of physical therapy methods and exercise after a breast cancer operation: a systematic review. *Critical Reviews in Physical and Rehabilitation Medicine* 13, 159–90.
- Kirshbaum, M.** 1996: The development, implementation and evaluation of guidelines for the management of breast cancer related lymphoedema. *European Journal of Cancer Care* 5, 246–51.
- Logan, V.** 1995: Incidence and prevalence of lymphoedema: a literature review. *Journal of Clinical Nursing* 4, 213–19.
- McNeely, M.I., Magee, D.J., Lees, A.W., Bagnall, K.M., Haykowsky, M.** and **Hanson, J.** 2004: The addition of Manual Lymph Drainage to compression therapy for breast cancer related lymphoedema: a randomized controlled trial. *Breast Cancer Research and Treatment* 86, 95–106.
- Megens, A.** and **Harris, S.** 1998: Physical therapist management of lymphedema following treatment for breast cancer: a critical review of its effectiveness. *Physical Therapy* 78, 1302–11.
- Mirolo, B.I., Chapman, M., Olsen, T., Eliadis, P., Hennessy, J., Ward, L.** and **Jones, L.** 1995: Psychosocial benefits of postmastectomy lymphedema therapy. *Cancer Nursing* 18, 197–205.
- Moffatt, C., Franks, P., Doherty, D., Williams, A., Badger, C., Jeffs, E., Bosanquet, N.** and **Mortimer, P.** 2003: Lymphoedema: an underestimated health problem. *Quarterly Journal of Medicine* 96, 731–38.
- Norman, S., Miller, L., Erikson, H., Norman, M.** and **McCorkle, R.** 2001: Development and validation of a telephone questionnaire to characterise lymphedema in women treated for breast cancer. *Physical Therapy* 81, 1192–205.
- Oncology Section of the American Physical Therapy Association.** 2000: Position statement: physical therapy: management of lymphedema in patients with a history of cancer. *Rehabilitation Oncology* 18, 9–12.
- Pain, S.** and **Purushotham, A.** 2000: Lymphoedema following surgery for breast cancer. *British Journal of Surgery* 87, 1128–41.
- Porteus, D.** 1996: Methodologies for needs assessment. In Percy-Smith, J., editor, *Needs assessments in public policy*. Buckingham: Open University Press.
- Scottish Executive.** 2003: *Partnership for care: Scotland's Health White paper*. Edinburgh: Crown Copyright.
- Scottish Intercollegiate Guidelines Network (SIGN).** 1998: *Sign 29: Breast cancer in women: a national clinical guideline*. Edinburgh: SIGN.

- Scottish Needs Assessment Program.** 1998: *Needs assessment in primary care: a rough guide*. Glasgow: Scottish Needs Assessment Program.
- Secker, J., Wimbush, E., Watson, J. and Milburn, K.** 1995: Qualitative research methods: some criteria for quality. *Health Education Journal* 54, 74–87.
- Sitzia, J., Woods, M., Hine, P., Williams, A., Eaton, K. and Green, G.** 1998: Characteristics of new referrals to twenty-seven lymphoedema treatment units. *European Journal of Cancer Care* 7, 255–62.
- Stevens, A., Raftery, J. and Mant, J.** 2003: An introduction to HCNA: the epidemiological approach to health care needs assessment. Retrieved 11 January 2003 from, <http://hcna.radcliffe-oxford.com>
- Tibbs, D., Sabiston, D., Davies, M., Mortimer, P. and Scurr, J.** 1997: *Varicose veins, venous disorders and lymphatic problems in the lower limbs*. Oxford: Oxford University Press.
- Tobin, M., Lacey, H., Meyer, L. and Mortimer, P.** 1993: The psychological morbidity of breast cancer-related arm swelling. *Cancer* 72, 3248–52.
- Woods, M.** 1993: Patients' perceptions of breast-cancer-related lymphoedema. *European Journal of Cancer Care* 2, 125–28.