

MAKING A CASE FOR FUNDING FOR LYMPHOEDEMA SERVICES

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Abstract

Background: Lymphoedema is a chronic condition which has a significant impact on the lives of sufferers. Services for lymphoedema management are not standard throughout the UK. Recently a request for funding of lymphoedema services in Fife required the creation of a needs assessment. **Aims:** The study aim was to establish whether or not lymphoedema presents a health-related need, addressing two main questions: do people with lymphoedema have a legitimate physical and/or psychological need for health care and do they benefit from the health care they are given? **Methods:** Qualitative interviews were conducted to explore the views of five lymphoedema service providers and five service users. Thematic analysis was undertaken. **Results:** Interview analysis indicated that the physical and psychological impact of lymphoedema has detrimental effects on daily function and participation in various aspects of life. Participants benefited from management, both physically and psychologically. Those with realistic expectations of management and who wished to take control of their symptoms expressed greater satisfaction with lymphoedema services. **Conclusions:** Lymphoedema leads to physical, psychological and social problems that can be alleviated through specialist management, thereby representing a health-related need. **Declaration of interest:** None.

Key words

Lymphoedema
Management
Health
Needs assessment

The purpose of this article is to justify the idea that lymphoedema presents patients with a health-related need that can benefit from health care, in order to inform requests for service funding and development. It stems from a needs assessment of lymphoedema services carried out in Fife, Scotland, and was funded by the Core Cancer Review Group in Fife (Bulley, 2003; 2007).

Although lymphoedema affects a large proportion of the population

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worldwide, there is a general lack of service funding and provision in the UK (Moffatt et al, 2003). In Fife, a small specialist lymphoedema service has been funded by the NHS since 1996. In 2003, a request for increased funding led to the commissioning of a needs assessment of lymphoedema services by the Core Cancer Review Group in Fife.

The epidemiological approach to needs assessment describes need as 'a desired end state' (Sanderson, 1996). Another definition states that a health need must have the capacity to benefit from health care (Crown, 1991). Therefore, a health-related need represents the desired outcomes that can benefit from health care. When seeking further funding for a service it is important to make the case for its importance. To make this case, lymphoedema must be seen as presenting people with a health-related need. This concept can be broken down by asking two questions:

1. Do people with lymphoedema have a legitimate need for help with its physical and psychological impacts?
2. Can the physical and psychological

impacts of lymphoedema be alleviated through healthcare provision?

These questions are first explored through a brief review of the literature.

Physical and psychological impacts of lymphoedema

In recent years, interest has grown in the impact of health on patients' quality of life (World Health Organization [WHO], 2005). There is evidence to suggest that the experience of cancer-related secondary lymphoedema reduces quality of life beyond the effect of cancer alone (Dorval et al, 1998). This negative impact is related to its effects on physical, psychological and social aspects of daily function, some of which are summarised in Figure 1.

Physical effects of lymphoedema impact on function and participation in social, domestic and occupational activities. Upper limb swelling reduces dexterity, strength and shoulder mobility, while lower limb oedema impairs mobility (Casley-Smith and Casley-Smith, 1997). There can also be significant discomfort and pain

(Pain and Purushotham, 2000; Morgan et al, 2005). Inevitably, functional abilities are affected, including self-care activities and occupational tasks (Tobin et al, 1993).

Research studies have highlighted various psychological and social reactions associated with lymphoedema (Woods, 1993; Hare, 2000). Both relate strongly to quality of life, which has received increasing attention in recent years. A rigorous review was carried out that sought all qualitative and quantitative research relating to this area in lymphoedema (Morgan et al, 2005). Cross-sectional and longitudinal studies found poorer psychological adjustment in people with lymphoedema compared with the general population. They also found greater incidents of anxiety and depression. Interestingly, two of the four relevant cross-sectional studies, and four of the eight longitudinal studies reviewed dealt specifically with individuals who had been treated for breast cancer. Of six international qualitative studies reviewed, all but one focused on experiences of upper limb swelling, while all six addressed cancer-related lymphoedema (Morgan et al, 2005). There were similar themes, with frequent descriptions of negative emotions, difficulties with body image and resulting social withdrawal.

A rigorous qualitative grounded theory study of 20 women with breast cancer-related lymphoedema described feelings of helplessness, loss and stigmatisation, anxiety and the need to make lifestyle changes (Hare, 2000). The women described feelings of guilt about its development, thinking that they could have avoided the trigger factor. Others have reacted with fear that the swelling is a sign of the cancer returning, or have felt it to be a constant reminder of the disease (Woods, 1993; Humble, 1995; Ridner, 2002). Many individuals have difficulties with their body image as a result of cancer, and this is exacerbated where they have chronic swelling in one or more limbs. Physical self-perception is strongly linked to self-esteem (Fox, 2000) and lymphoedema can have a significant effect on social and sexual confidence.

Two early studies of psychosocial function were carried out in women with

breast cancer-related lymphoedema. One compared 50 lymphoedema sufferers with 50 matched controls (Tobin et al, 1993), while the other carried out a non-controlled, longitudinal study of 40 women at referral for treatment and after six months (Woods, 1993). Both used the same self-report questionnaire to assess adjustment in a variety of psychosocial domains. In comparison to controls, lymphoedema patients had greater impairment of physical function. There was greater disruption to sexual relationships in the group with lymphoedema, with a loss of interest in dress and appearance, reduced self-esteem and less interest in social activities (Tobin et al, 1993). The longitudinal study supported this; disruptions to body image and confidence in personal appearance were perceived to be among the greatest problems (Woods, 1993).

Although the research base is not highly developed and more work is required into lymphoedema from all causes, these studies strongly support the idea that lymphoedema leads to physical, psychological and social needs.

However, can these problems benefit from health care?

Do people with lymphoedema benefit from health care?

The specialist management of lymphoedema was advocated in the 2002 National Institute for Clinical Excellence (NICE) guidelines for improving outcomes in breast cancer, although specific recommendations were not provided. Consensus is demonstrated in practice guidelines and position statements from the UK, Canada and the USA (Kirshbaum, 1996; Oncology Section of the American Physical Therapy Association, 2000; Harris et al, 2001). A model of specialist lymphoedema services was developed in a project sponsored by Macmillan Cancer Relief (Badger and Jeffs, 1997). More recently, the UK-based Lymphoedema Framework Project has conducted a rigorous consensus development project, leading to a set of national standards and a Best Practice document (Morgan et al, 2006).

Lymphoedema management aims to develop patient empowerment and

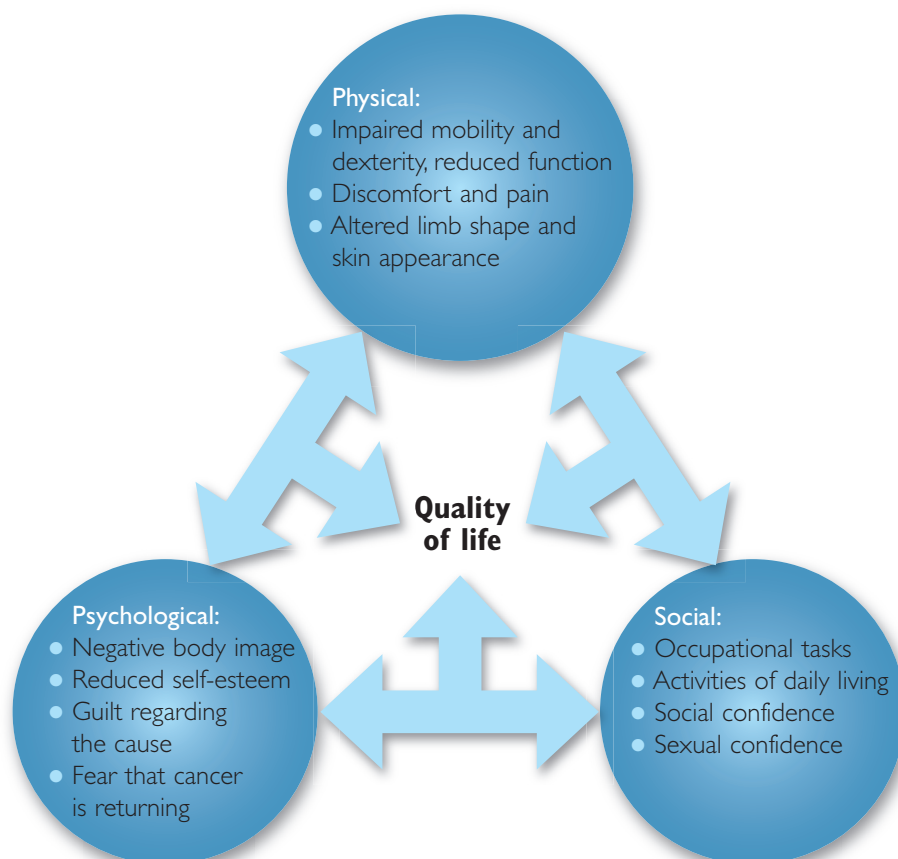


Figure 1. A summary of interacting physical and psychosocial impacts of lymphoedema.

satisfaction through education and training in self-management techniques. First, a reduction in limb volume and improved shape, mobility and function are sought. Complex decongestive therapy (CDT) is used, a combination of techniques that include manual lymphatic drainage (MLD), compression bandaging and garments, gentle exercise, skin care and advice (Badger and Jeffs, 1997). Once limb volume and shape are optimal, the emphasis shifts towards control of the improved size, shape and function of the limb through continued use of compression garments, exercise and skin care activities. Finally, palliation is associated with treatment aims that emphasise symptom relief rather than optimising volume and shape.

Despite the consensus achieved in relation to lymphoedema management aims and strategies, it is important to be aware of the evidence base. Comparison is difficult because of a lack of standardisation in management programmes and outcome measurement. One author described the evidence base as insufficiently rigorous, with predominantly descriptive studies that support most interventions being investigated as effective in reducing limb volume (Sitzia and Harlow, 2002).

One critical review focused on interventions for lymphoedema secondary to breast cancer (Megens and Harris, 1998). Of 13 trials, none were randomised and controlled and only nine operationally defined lymphoedema, using five variations. Reliability of the eight different outcome measures was mentioned in four studies and none described validity. Conclusions suggested the efficacy of complex decongestive therapy and compression garments.

Despite the lack of standardisation in study design, there is evidence for improvements in limb volume and condition of the lymphatic system. A recent systematic review of 31 studies, found that two demonstrated statistically significant positive effects of massage, compression, exercise and skin care (Karki et al, 2001). However, the widely varying studies made comparisons difficult. Two randomised controlled trials have found significant

improvements in limb volume after MLD and compression, with the addition of exercise in the later study (McNeely et al, 2004; Didem et al, 2005). Both found more significant improvements where lymphoedema was mild at baseline.

The research evidence favours the efficacy of management, suggesting that lymphoedema can benefit from health care. However, carefully designed and standardised studies are needed in relation to the separate therapeutic components, to determine optimal management programmes.

Evidently, there is research to support lymphoedema as presenting a health-related need. However, it is important to explore the impact of the disorder on individuals' lives, and the potential for its alleviation in the local context, especially where there is an underdeveloped evidence base. The Scottish Executive places a high priority on the views of service users, stating: 'looking at services from a patient's point of view underpins everything that we are seeking to do in the health service' (Scottish Executive, 2003). To further evaluate the case for lymphoedema treatment as a health-related need, a qualitative study was

carried out to explore the views and experiences of lymphoedema service providers and users in Fife.

Methods: qualitative interviews of lymphoedema service providers and clients

This exploration represents one component of a larger study which aimed to explore perceptions of the needs of individuals with lymphoedema, and the impact of management on their lives. Qualitative interviews were carried out and analysed within a postpositivist philosophical approach (Secker et al, 1995). This assumes that there is a commonality of experience that can be imperfectly understood using research methods. In contrast, a constructivist approach would focus on the variety of individual experiences. However, as the study aim was to collect evidence regarding the needs of individuals with lymphoedema, to be used in recommendations for service development, the postpositivist approach was considered more appropriate, as it focuses on establishing a 'general reality' experienced by different individuals. Despite its view of a general truth, this approach is critical of its ability to fully and accurately comprehend that reality, and values triangulation of findings from

Table 1

Summary of lymphoedema services and interviewees in Fife

Service	Staffing level	Service users	Interview participation
Queen Margaret Hospital lymphoedema service (NHS funded)	One physiotherapist 2.5 days per week; one physiotherapist 0.5 days per week	Primary and secondary lymphoedema	Senior I physiotherapist Five service users
Victoria Hospice palliative care service (NHS funded)	One physiotherapist One nurse	Lymphoedema care provided to clients of the palliative care service as part of a package of care	One senior I physiotherapist One nurse
Independent practitioner (privately funded)	One independent practitioner with specific training	Primary and secondary lymphoedema	One independent practitioner
District nurse (NHS funded)	One district nurse	Non-specialist assistance provided to the palliative care service in home care of individual patients	One district nurse

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different sources and/or methods. In this case, two sources are included: interviews with providers and users of lymphoedema services in Fife.

Recruitment

A small, purposive sample of clients at the Queen Margaret Hospital lymphoedema service was sought in order to include individuals with both primary and secondary lymphoedema, affecting upper and lower limbs. This was carried out to ensure that individuals with primary lymphoedema were given the opportunity to describe their experiences, which might differ from those with secondary lymphoedema. Table 1 provides a summary of participants. The study was supported by two consultants and the hospital medical director. Ethical approval was granted by the Fife NHS Board Local Research Ethics Committee.

Table 2

Interviews with service providers: questions, emergent themes

*What do you feel are the needs of individuals with lymphoedema?
What do you aim for as an outcome of treatment?*

Themes:

- ▶▶ Aims and outcomes of treatment
- ▶▶ Rationale for the intensive and maintenance phases of management
- ▶▶ Quality of life
- ▶▶ Social needs
- ▶▶ Cosmetic needs relating to body image and self-esteem that may be met by lymphoedema services
- ▶▶ Alleviation of pain and discomfort
- ▶▶ Information and support
- ▶▶ Function and lifestyle — needs relating to mobility, the ability to function in everyday life and potential adjustment to lifestyle that may be met by lymphoedema services
- ▶▶ Prevention of infection such as cellulitis

Interviews

A single interviewer conducted all the semi-structured interviews and data analysis. Topic guides were reviewed and approved by a member of the Core Cancer Review Group. The questions relevant to the topic of this paper are included in Tables 2 and 3. Probing questions were used to explore views in more depth, while reflecting responses back to participants enabled clarification of responses and confirmed the researcher's interpretation. Interviews lasted up to one hour and were recorded for later transcription.

All providers who were located and approached consented to participate in the study. Interviews were carried out with five lymphoedema service providers at their places of work: one physiotherapist provided a part-time service funded by the NHS, two clinicians delivered lymphoedema management as part of a palliative service, and one lymphoedema practitioner operated a private practice. One district nurse was involved in assisting the palliative care service in the provision of home care.

Seven clients of the Queen Margaret Hospital lymphoedema service were

Table 3

Interviews with service users: questions, emergent themes

*How would you describe the effects of lymphoedema on your life?
How has receiving treatment affected you?
What are you and your therapist aiming for in your treatment?*

Themes:

- ▶▶ Physical symptoms
- ▶▶ Psychosocial symptoms that affect an individual's life
- ▶▶ Functional effects of lymphoedema on daily life and function
- ▶▶ Treatment aims
- ▶▶ Effects of treatment on an individual's symptoms and daily life
- ▶▶ Feelings regarding treatment

sent the information sheet by their physiotherapist and five were willing to participate. Two of the women had unilateral primary lymphoedema of the lower limb (duration: five years and eight months), and three women had unilateral secondary lymphoedema of the upper limb following breast cancer (duration: six months, 18 months and 12 years). All were in the maintenance phase of treatment. Individual interviews were arranged, appropriate to the confidential nature of the discussions. They were conducted in a familiar and comfortable location. Informed consent was provided in the presence of a witness.

Data analysis

Transcribed interviews were analysed for broad themes within the study questions. A theme is defined to differentiate between similar or unique experiences or views. Coding of themes and supporting text units allows tracking of this analysis process, ensuring transparency and rigour. Triangulation of findings from interviews with service providers and clients enabled greater understanding and trustworthiness (Grbich, 1999).

Results

Individual views and experiences were explored and emergent themes relevant to the topic of this paper are summarised in Tables 2 and 3.

Physical and psychological needs

Needs described by individuals with lymphoedema were in line with the perceptions of service providers. Themes are classified under physical and psychological symptoms and functional effects (Table 3). All service clients described swelling as their initial symptom. One interviewee, with primary lower limb lymphoedema, remembered that her lower leg had felt solid, with cold, paper-thin, dry skin that 'felt like if you touched it, it would break'. Two clients described feeling tired from 'carrying the weight' of their heavy limb. A service provider explained that pain and discomfort are often the greatest problem for patients. Two of the clients interviewed described pain; one had particularly severe experiences of it, describing related feelings of helplessness and depression.

One service provider explained that impaired function has a negative effect on psychological well-being and ability to fulfil social roles. On interview, clients with lower limb lymphoedema described difficulties mobilising, while those with upper limb swelling had difficulties with grip strength, dressing, food preparation and other daily tasks.

A service provider explained that body image disturbances, already frequent for people with cancer, were exacerbated with lymphoedema. Another explained that 'some individuals worry about what clothes they can wear... it can have a psychological effect'. The effect was thought to be so great that women often found it difficult to look in a mirror. These perceptions were supported by individuals with both primary and secondary lymphoedema; several service

users described difficulties in shopping for shoes and clothing. One felt angry and upset about having 'two odd legs'. Another client found it hard 'coming to terms with wearing a sock that does not look at all feminine'. In contrast, one of the women felt that, 'in the scheme of things I had a mastectomy... other things could happen that are a lot worse'.

Several individuals found adjusting to living with this chronic disorder traumatic and felt the need for support. They described anger and difficulties in accepting the impact of lymphoedema on their lives. One service provider supported this, explaining that many patients need to go through 'a phase of acceptance that they have this condition and it isn't going to go away'. Helping individuals to develop realistic expectations regarding their

chronic condition was thought to be an important part of management.

Impact of management

The focus of management was described by all service providers as improving quality of life. In the palliative care service, intervention varied according to need. One clinician explained, 'the burden of the intervention should never outweigh the outcome', and another added, 'the intervention may be more cumbersome than the oedema'. Non-palliative services aimed to reduce and control swelling and improve function. The clients interviewed provided further evidence for these aims. Three women explained that the swelling in their limbs had been reduced through therapy, and that their current aims were to increase mobility and further reduce, or maintain, limb volume.

It is important to explore whether individuals feel that their needs are being met by lymphoedema management. The specific role of a lymphoedema service in providing information, explanation, support and reassurance was raised in interviews with both providers and clients. Information and advice may aim to prevent further deterioration, to develop realistic expectations, and provide reassurance. One client described feeling delighted that she could talk to someone who 'knew what they were talking about'. However, not all individuals were satisfied with management, which appears to be affected by expectations of outcomes.

Experiences of lymphoedema and the impact of management

Interview analysis revealed that the impact of treatment related to expectations (Figure 2). For example, three women who had all experienced physical and functional improvements from therapy, and who had realistic expectations, were very satisfied with management. One client stated, 'keeping it like this, I feel I am able to do most of the things I want to do'. Another woman explained, 'each time I feel I am making progress. I am thrilled to bits when I come in and [the swelling] is down a bit'. However, two women who had hoped for a cure were less satisfied with management, stating, 'I don't think I am going to get rid of it', and, 'I wish it would

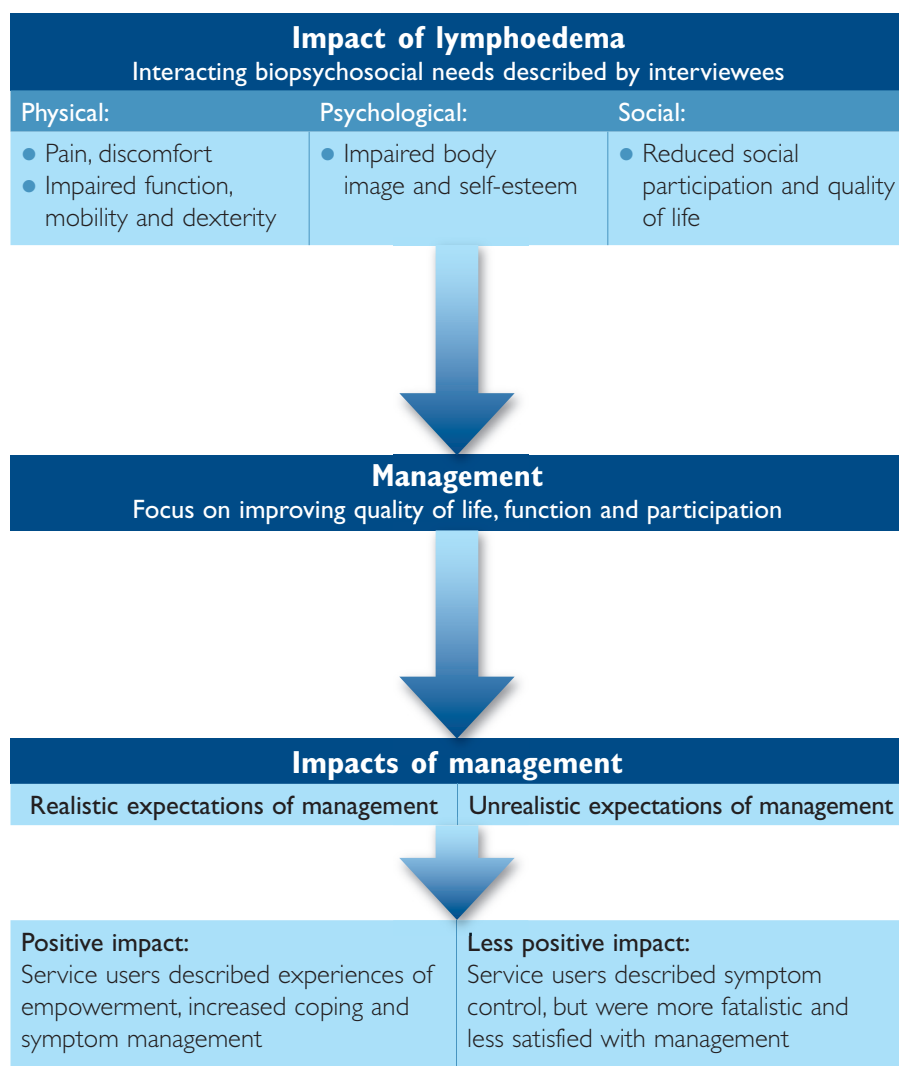


Figure 2. Schematic representation of the impact of lymphoedema and its management on service users in Fife.

disappear, but I don't think that would ever happen now.' They had endured the condition for longer and did note that their limb volume had not increased during this time.

The women who described the most benefit from lymphoedema management were those who expressed a need to take some personal control of the problem, explaining, 'if I am physically able to do something for myself, I feel better', and, 'I like to be in charge... to know that I can make a difference.' These clients were enthusiastic about learning the skills and knowledge necessary for self-management.

Discussion

The experiences of individuals with lymphoedema in Fife were very much in line with those reported in the literature. The physical impacts of swelling on mobility and dexterity had an effect on function. Experiences of significant pain led to feelings of depression and hopelessness, while women felt inhibited by the cosmetic impact of having a swollen limb. The need for relief of these problems was described by service users and providers. Findings in the local context of Fife triangulate with similar experiences found in previous quantitative and qualitative studies (Tobin et al, 1993; Woods, 1993; Hare, 2000; Morgan et al, 2005).

It was encouraging to see that users of the lymphoedema service in Fife described symptom relief and control from treatment, which is supported by a slowly-developing evidence base for the efficacy of lymphoedema management (McNeely et al, 2004; Didem et al, 2005). However, randomised controlled trials would not necessarily provide in-depth information regarding the effects of treatment. Several of the interviewees had felt a deep need for someone with expertise who could guide and inform them, but wished to take as much control of their own management as possible. They also had realistic expectations of management and expressed greater satisfaction with their progress. This subgroup included one woman with primary, and two with secondary lymphoedema. The needs described by this group

of women were similar to a previous qualitative study, where a predominant theme indicated the importance of finding out and receiving information (Hare, 2000). The importance of providing a supportive and advisory role was also described by service providers in Fife.

These findings demonstrate the importance of appropriate management for lymphoedema, as a long-term condition with significant impacts on quality of life. The need for services that support individuals in managing long-term conditions has received a lot of attention recently. The Department of Health has promoted an 'NHS and social care long-term conditions model' which emphasises the need to support people appropriately in the community, preventing escalation of health problems to the point of hospitalisation (Department of Health, 2005). Effective management is required to prevent the development of lymphoedema in at-risk groups, and prevent its deterioration. Inadequately managed lymphoedema can lead to acute inflammatory episodes (sepsis) that may require hospitalisation (British Lymphology Society [BLS], 2001). As lymphoedema becomes more advanced, the time and resources required to manage the condition are more significant and the impact on function and quality of life are greater (Sitzia et al, 1998). However, if lymphoedema is detected early and individuals are supported well, specialist management required is likely to be minimal.

The findings in this study have several uses. First, they contributed to the development of a case for increased service funding in Fife. Although this study took place in 2003, the clinical context does not appear to have changed dramatically in the UK. It is likely that the findings are still relevant, as services are still sparse. It will become increasingly necessary to advocate for service development as the range of healthcare interventions continues to increase.

This study focused on a small number of individuals, but included people with both upper and lower limb lymphoedema of varied duration. This ensured a variety

of experiences and greater depth of understanding. Sample extensiveness refers both to interview number and length in qualitative research (Safman and Sobal, 2004). Interview length varied from about 40 to 60 minutes, providing extensive data for analysis. This study aimed to explore a general reality for individuals with lymphoedema that could be used to inform service development. A constructivist approach can also be used to focus on in-depth understanding of individuals' experiences. This would have the added value of addressing the variety of individual experiences and beliefs that may influence participation in, and quality of, daily life. Greater understanding would inform service providers, enabling them to better facilitate individuals in coping with lymphoedema and participating in their own care.

The study achieved its aim to construct a case for lymphoedema treatment as a health-related need and continued by exploring the extent to which local services are meeting the need identified. Recommendations for service funding and development were made based on this study and will be reported elsewhere.

Conclusion

The status of lymphoedema management as a legitimate response to patient need has been supported by previous studies and interviews with lymphoedema service providers and clients. The literature review demonstrated that further research is required, including an exploration of therapeutic outcomes sought by individuals suffering from different types of lymphoedema. More well-designed trials are needed to search for the optimal combination and intensity of treatment strategies. It is important to understand the influences of experience, coping and therapeutic styles on participation in care and efficacy of management, in both primary and secondary lymphoedema.

Despite the deficits in the current evidence base, a variety of studies indicate that lymphoedema affects mobility, dexterity and function. These, added to experiences of pain and body image disturbance, reduce individuals' quality

of life. Local and international evidence from quantitative and qualitative studies suggest that people with lymphoedema have needs that can benefit from health care. Although more research is required, this will be developed more rapidly in a context of funded service delivery. JL

Acknowledgements

Thanks to: the Core Cancer Review Group for funding the needs assessment; Queen Margaret Hospital, Dunfermline, for supporting the study; Rikky McPhee, Claire Mitchell, Kate Ingebrigsten, Lynora Kennedy, and Barbara Lyle for their expert advice; and all those who participated and assisted with this study.

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Key points

- ▶ Lymphoedema services are not distributed equitably in the UK and there is competition for resources in the NHS.
- ▶ In order to make a case for increased funding, it is important to demonstrate that people with lymphoedema need treatment and can benefit from healthcare provision.
- ▶ The research base is underdeveloped, but provides evidence for the physical, psychological and social impacts of lymphoedema on individuals, and the potential for lymphoedema management to improve function and quality of life.
- ▶ Thematic analysis of qualitative interviews with five providers and five users of lymphoedema services in Fife provides support for lymphoedema as a health-related need.