

A phenomenological study of the lived experiences of people with lymphoedema

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Abstract

Lymphoedema occurs in all age groups and is caused by lymphatic insufficiency. It is associated with a wide range of cancer- and non-cancer-related conditions. Researchers have explored the impact of lymphoedema on quality of life but most studies have focused on breast cancer-related lymphoedema or used specific quality of life tools. The study reported here used a phenomenological approach to explore the lived experience of 15 individuals with different types of lymphoedema. Findings highlight the uncertainty surrounding their diagnosis, the difficulties they experienced in accessing appropriate treatment and ways in which they dealt with having lymphoedema. Recommendations are made highlighting the need for increased awareness of lymphoedema and the importance of wider consideration of the emotional and psychosocial dimensions of this chronic condition.

Lymphoedema has been estimated to be present in over 1.33 per 1000 population (Moffatt et al, 2003) and occurs in all age groups. Swelling, caused by a failure of the lymphatic system (Keeley, 2000), usually affects one or more limbs and may be complicated by an oedema of the trunk, head or genitalia. Cancer-related lymphoedema occurs most commonly after treatments for breast cancer, gynaecological cancers and malignant melanoma (Keeley, 2000). Non-cancer-related lymphoedema can develop in the early years as a congenital primary lymphoedema (Browse, 2003) but is also associated with venous ulceration, traumatic injury and infection (Mortimer, 1995).

Lymphoedema management involves a combination of physical therapies, including manual lymphatic drainage (MLD) massage, compression therapy, exercise and skin care to reduce swelling and improve quality of life (Todd, 1998). Initially, individuals may require an intensive treatment programme, often referred to as Decongestive Lymphoedema Therapy (DLT) (British Lymphology Society, 2001) and consisting of daily MLD massage and bandaging over a period of 2–4 weeks. This is followed by a period of self-care, referred

to as the maintenance phase. The long-term success of this phase relies on the active participation of the person with lymphoedema in a programme of regular self-massage and exercise, skin care and wearing of hosiery garments.

Literature review

The literature highlights the considerable physical, psychological and economic burden of lymphoedema (Tobin et al, 1993; Sitzia and Sobrido, 1997; Poole and Fallowfield, 2002; Moffatt et al, 2003). The majority of research has focused specifically on breast cancer-related lymphoedema. Tobin et al (1993) used the Psychological Adjustment to Illness Scale (PAIS), reporting difficulties in relation to domestic environments and sexual relationships in women with breast cancer-related lymphoedema. Shock and fear about cancer recurrence, frustration and difficulties relating to body image, altered sensations in the limb, difficulties with clothing and lack of confidence have also been identified in this group (Woods, 1993).

Beaulac et al (2002) used the Functional Assessment of Cancer Therapy-Breast (FACT-B) quality of life tool and highlighted significantly low scores in those with lymphoedema, while Velanovich and Szymanski (1999) described the changes in quality of life demonstrated by the SF-36 generic quality of life tool. A review of the literature on the psychological impact of arm morbidity following breast cancer suggests, however, that there is a need for careful selection of appropriate condition-specific outcome measures in this group, as many generic tools are not adequately sensitive to the particular problems affecting this population (Poole and Fallowfield, 2002).

A few authors provide insight into other groups with lymphoedema. A prevalence study of people with all types

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of lymphoedema reported pain in 50% of participants and described 9% as stating that lymphoedema affected their employment status (Moffatt et al, 2003). Sitzia and Sobrido (1997) highlighted the problems with pain experienced by those with lower limb swelling, describing the improvements in some areas of quality of life following treatment, as measured by the Nottingham Health Profile. However, the authors identify the shortcomings of this tool for use in lymphoedema. Similar treatment-related improvements, particularly in those with lower extremity lymphoedema, have also been reported (Weiss and Spray, 2002).

Although the literature reflects various approaches to exploring the impact of lymphoedema, most studies use quality of life tools not specific to lymphoedema and many focus solely on breast cancer-related lymphoedema, providing limited insight into the experiences of those with lower limb swelling. Exploring the lived experiences of people with various types of lymphoedema provides the opportunity for deeper understanding and awareness of the impact of lymphoedema on different individuals.

Research approach

This study used a phenomenological research approach to describe the experiences of people living with lymphoedema and explore individuals' experiences of lymphoedema treatment through the use of audiotaped, in-depth interviews.

Phenomenology is rooted in the belief that human meaning can be understood only through the experiences of individuals within their given situation (Husserl, 1970). The phenomenological research approach seeks to investigate the lived experience of individuals and the way in which they understand their experience (Depoy and Gitlin, 1994). This approach depends on the willingness of those indi-

viduals to reveal their experiences and their ability to express themselves. Importantly, it also requires the researcher to set aside his/her preconceived ideas and assumptions about the phenomena in question. This process of bracketing encourages openness and a reflective approach towards the subject area, in seeking to provide objectivity within the findings (Koch, 1995).

Sampling method

Participants were drawn from a specialist lymphoedema clinic in the London area. A purposive sampling method was used to identify individuals who could provide insight into the phenomenon in question. Individuals with a spectrum of types and severity of lymphoedema were identified. This sampling method was felt to be important to obtain a wide perspective on the subject area.

Those included in the study were males or females aged over 18 years with a medical diagnosis of lymphoedema of over 3 months duration, who had attended the local lymphoedema clinic within the previous 3 months and were able to provide written informed consent.

Data collection

Demographic and baseline information was obtained for each participant from their lymphoedema clinic notes and included age, type of lymphoedema, duration and area of swelling, past lymphoedema treatments and social/family situation. Data were collected using in-depth interviews with participants, in private. Each interview lasted around 1 hour and was audiotaped. A number of discussion prompts were used by the researcher to encourage participants to elaborate on issues of particular relevance or importance to themselves (Table 1).

The purpose of the phenomenological interview is to describe and understand the individuals' experiences and interpretations, and involves the interviewer in listening and narrative (Sorrell and Redmond, 1995). This is a participative interview where the interviewer needs to shape the interview but is also shaped and led by the interview process. Open, probing questions are used to allow participants to describe their unique experiences. The use of silence is also an important feature, as it allows the participant time for reflection on their thoughts (Van Manen, 1990).

Table 1. Examples of interview discussion prompts

Could you tell me what it was like for you when you first discovered you had lymphoedema/when your arm/leg started to swell?

Tell me more about how lymphoedema has affected you and your daily life

What are the most difficult things about having lymphoedema?

Please describe your experience of lymphoedema treatment

How would you judge if treatment had been successful?

Could you tell me more about how you felt about that particular experience and what it meant to you?

Ethical considerations

Permission to conduct the study was granted by the ethical approval committee for the local NHS Trust. Potential participants were informed verbally and in writing about the aims and procedure of the study and were given the opportunity to ask questions about the study before giving written consent. It was recognized that the probing discussion could be difficult and potentially threatening for some participants who may find it difficult to discuss their experiences openly. Care was taken to provide a relaxed, private and non-threatening environment for the interviews and it was made clear to the individuals that they could withdraw from the interview at any point should they wish. Confidentiality and anonymity was assured and audiotapes were destroyed at the end of the study analysis. All attempts were made to ensure individuals could not be recognized from the data.

Data analysis

Audiotapes were transcribed verbatim by an independent transcriber. The researcher then listened to each narrative on the tape, checking it against the transcript for accuracy and timing. Specific features of the interview, such as episodes of silence, laughter or evidence of emotional distress, were noted on the transcript.

Each transcript was then read to elicit an initial feeling for the individuals' experience and ideas. The transcripts were then examined in more depth using a technique known as 'open coding' (Strauss and Corbin, 1990). Words and phrases relating to the phenomenon were extracted and labelled as codes. Once the various codes were identified for each participant, they were organized into themes (Colaizzi, 1978). As the data from each participant were integrated and compared, these themes were further refined, identifying patterns and possible interconnections within and between them. Finally the

main phenomena were established and described in relation to a number of themes, some of which reflected the words used by participants. Ideally at this stage the phenomenological researcher should return to the participants to validate the findings and obtain their views on the data. Unfortunately this was not practical within the time restraints of this study.

Results

A total of 15 participants took part in the study, reflecting individuals with a range of types of lymphoedema (Table 2). Because of lack of time, it was impractical to undertake more interviews and the initial 15 interviews provided a broad sample, with an intentional focus on individuals with primary lymphoedema, as this group is under-represented in the literature. Mean age was 57 years (range 35–89 years) and there were 12 women and 3 men. Primary lymphoedema was defined as swelling caused by a congenital or hereditary insufficiency in the lymphatic system (Browse, 2003). Secondary lymphoedema was identified as swelling resulting from damage to the lymphatics because of problems such as cancer treatment, injury, leg ulceration or infection (Keeley, 2000). The duration of lymphoedema ranged from 1–41 years. Those with cancer-related oedema tended to have a shorter history of swelling, although one had breast cancer-related lymphoedema for 19 years.

The data from the study were comprehensive and a range of themes emerged, identified within three main phenomena (Table 3). A number of these themes have been highlighted for discussion here.

The experience of lymphoedema diagnosis

Difficulties in establishing a reason for the swelling and being provided with appropriate information were apparent in most narratives, to various degrees. This appeared to be linked to a general lack of knowledge and awareness about lymphoedema, particularly within the medical profession.

Uncertainty

A number of participants, particularly those with primary lymphoedema, had suffered swelling and associated ill health for many years before being given a correct diagnosis and their experiences seemed fraught with uncertainty and associated anxiety. In several instances, the wrong diagnosis had been made in the past and participants had been

Table 2. Causes of lymphoedema in research participants

Type of lymphoedema	Number of participants
Breast cancer-related lymphoedema	3
Cervical cancer-related lymphoedema	2
Carcinoma of the penis related lymphoedema	1
Primary lymphoedema of the legs	7
Lymphoedema of the legs secondary to venous insufficiency	2

treated inappropriately. In particular, infective episodes appeared to be poorly managed, causing exacerbation of the swelling over many years.

'... there was no explanation for the fact I was getting high temperatures and... the fact the swelling wasn't going down... it lasted for quite a while... they couldn't figure out the reasons for it...'
(Participant 5)

'it started to swell and I didn't know, I didn't have a clue... I went through several diagnoses.'
(Participant 1)

These descriptions from women with primary lymphoedema contrast with the experiences of those with cancer-related lymphoedema who appeared to be diagnosed more quickly:

'as soon as I saw the swelling I went... (to) my GP... oh... he said, you had a mastectomy, which of course I knew, and he said people do sort of get this kind of swelling after'
(Participant 3)

Anxiety, fear and sorrow associated with the diagnosis of lymphoedema was also described by a number of participants and is illustrated by one woman having radiotherapy for cervical cancer who recounts her experiences of a sudden onset of swelling in her leg:

'I remember the first day... I was so frightened... and the swelling was there... fortunately I was still going to the hospital every day so I went and I showed the doctor... and he said to me oh it's that again and I said what is it and he said well a couple of people had

that after the radiotherapy but I wasn't told so I was really broken-hearted.'
(Participant 7)

Fishing in the dark

Most participants reported not being given adequate information around the time of lymphoedema diagnosis. The phrase 'fishing in the dark' was used by a woman with breast cancer-related lymphoedema as she commented on the general lack of lymphoedema awareness within the hospital stating:

'but if the health care system is also fishing in the dark what can one say'
(Participant 3)

Further difficulties once the lymphoedema was diagnosed and they had been given some information were also apparent:

'eventually I was given a diagnosis of lymphoedema and was basically told that was it. I wasn't given any help, nothing, so I didn't know how to keep it under control, then later I was given a bit more information but even then I don't think I really understood... what it was going to be like... it was all too new and I hadn't come to terms with what was wrong with me'
(Participant 1)

Tension with health-care professionals

Most participants reported specific difficulties in their relationship with doctors because of the lack of interest and medical awareness about lymphoedema and, in some cases, the fact that they had not been warned of their risk of developing lymphoedema.

'the surgeon didn't tell me it was going to happen... I rang him and he said... it will go, could you persevere, now you haven't got the cancer you should be happy about that... you have just to put up with it.'
(Participant 10)

'[the doctor] was totally disinterested in my lymphoedema I said tamoxifen is upsetting my lymphoedema and he said well can't you take diuretics and I said no... and I can't be bothered to explain any more he just said to me you look fine when you're here and then I said a stupid thing... try living with it and he

Table 3. Described phenomena and relevant themes

1. The experience of lymphoedema diagnosis

- Uncertainty
- Fishing in the dark
- Tension with health professionals

2. Experiencing and dealing with lymphoedema

- Facing others – the social stigma
- Keeping it hidden
- Rehearsing the story and learning to open up
- Making sense of it
- Getting on with it

3. Lymphoedema treatment

- Starting on a firm footing
- Knowing what I need
- Reading my body and judging the effect

'Some expressed the fact that this was the first time anyone had sat and listened to their story.'

just looked... but if it's been caused by an operation they should want to put it right'

(Participant 3)

'I actually felt quite belittled by him. I was told you've got lymphoedema it doesn't look that bad... the way it was dealt with I felt really stupid and I felt like I was bothering them with a problem that really wasn't [wasn't] very important on the scale of things, I was made to feel like a silly women really'

(Participant 1)

Experiencing and dealing with lymphoedema

The psychosocial, emotional and personal impact of lymphoedema was described in detail by all participants and highlights the ongoing experience of living with this chronic condition. Not surprisingly, most participants identified difficulties in their relationships with family or friends, along with feelings of isolation and exclusion. Some were tearful in the interviews and the devastating effects of lymphoedema became apparent, particularly in the younger women with primary lymphoedema, many of whom appeared to have problems with depression and anxiety. Some expressed the fact that this was the first time anyone had sat and listened to their story.

'I lose my patience so quickly... I get into depression... some days I do cry about it... it may just be out of the blue for no reasons... sometimes like in the mornings... I can't even get out of bed'

(Participant 4).

Facing others – the social stigma

A number of emerging themes interconnect here as the participants talked of the difficulties in facing others, the social stigma and isolation.

'I've always worried about people's reactions... I mean I've noticed a couple of times when I go to the swimming pool, as soon as they see the leg, it's like their reaction is maybe it's infectious... whether it's intentional or not, some people do get out the pool.'

(Participant 5)

'I hated people drawing attention to it... it felt like everyone focussed on the leg not me'

(Participant 12)

Keeping it hidden

Difficulties with self-image were strongly reflected in the interviews with the younger women with primary lymphoedema, all of whom talked of how they kept their legs hidden and had particular difficulties with wearing skirts and finding shoes to fit. Generally the men and the older women seemed less worried about their appearance. Specific problems of genital oedema raised various personal issues and embarrassment for one woman:

'even having a daily bath and creaming myself and this sort of stuff I find that quite disgusting'

(Participant 9)

'I was at the bank and someone said oh I don't think your zip is done up and, well it was but my trousers were sort of bulging, I just said, well I've got funny underclothes, but I was so embarrassed'

(Participant 9)

Rehearsing the story and learning to open up

The issues around communicating with others, talking to others about their condition and being open with friends and family were clear. Narratives described participants' frustrations with others' lack of knowledge about lymphoedema and the way they dealt with comments from others, by rehearsing what they might say.

'I had a problem opening up about it to people, I still do, sometimes with new friends... it takes me a while to open up to them'

(Participant 12)

'I think up different answers for different people'

(Participant 11)

'they don't really understand the condition... so it's quite difficult to explain it to people... it's very difficult for people to comprehend what's wrong with you... I suppose you're not really ill but you're not right either'

(Participant 13)

Making sense of it

Participants used a variety of strategies to make sense of having lymphoedema, including comparing it with various life-threatening conditions or rationalizing that having lymphoedema might be 'some-

'Comments suggested that coming to the lymphoedema clinic had enabled the participants to understand their condition and feel more in control.'

thing to be thankful for', as a 'trade off for beating cancer'.

'the fact I had my surgery 22 years ago – that's something to be thankful for'
(Participant 11)

'this is nothing compared to what I've seen... my husband's friend's got motor neurone disease and that's life threatening to me this is nothing'
(Participant 12)

Getting on with it

A variety of coping strategies were evident. The need to move on, coupled with a type of positive resignation to having lymphoedema, was seen within the theme of 'getting on with it'. Participants also described ways in which they were adjusting and adapting to having lymphoedema.

'I would really like to start getting on with it now, I am trying to be positive... I think a lot of it is mind over matter'
(Participant 3)

'You get this leaflet when you get lymphoedema, telling you how to rethink your life and it's almost as if you're going to be disabled, well I've just adapted the way I do things... you adapt the house... although it doesn't look it, there's a grab rail in the bathroom that's neatly tucked out of sight... and a few other things that people won't notice'
(Participant 8)

Some of the coping tactics appeared to be emotion-focused and involved some level of denial. For example, one woman described her early resistance to finding out about lymphoedema and reticence to wearing hosiery. Similarly, efforts to make a joke of the swelling and 'bury it' were described. One woman with primary lymphoedema described how, over a period of time, she slowly adjusted to having lymphoedema:

'... but it did take a long time, a lot of tears, a lot of frustration'
(Participant 12)

Lymphoedema treatment

Starting on a firm footing

The opportunity to have the condition recognized and treated after years of being without help was seen as particularly important, although the anxiety about the future was also evident:

'it almost felt like a bit of a haven... there were people there who knew about it [lymphoedema] and could give you the stuff you needed... it was like a relief'
(Participant 1)

'I do get worried that the support's going to disappear... knowing that things get set up on a short term basis... what to me might be a huge improvement on a piece of paper might not look very interesting or worthwhile but to me psychologically it might make a huge difference'
(Participant 1)

Knowing what I need

Comments suggested that coming to the lymphoedema clinic had enabled the participants to understand their condition and feel more in control. It was also clear that continuity of care was important with participants recognizing the need to have regular reassessment and new hosiery garments in order to help control the lymphoedema and keep them motivated towards their self-care activities. A male participant commented on the need to be 'kept in the picture' about his lymphoedema and another described regular follow up as giving her 'a bit of confidence'.

Discussion around the various aspects of treatment suggested that while the experience was generally positive, participants also recognized difficulties. The intensive, daily treatment programme was found to be tiring and two participants with primary lymphoedema described the trauma of being bandaged commenting:

'you can't hide it when it's bandaged like this, it's in your face quite literally'
(Participant 15)

'the first time I was bandaged, I left and sobbed my heart out'
(Participant 12)

Several participants talked of having to prepare themselves well in advance for the intensive treatments, both practically and psychologically. This was important as the bandages were felt to be disruptive, affecting their ability to drive, undertake housework and care for their family.

Reading my body and judging the effect

Narratives highlighted the ways in which some participants had become experts in their own care needs and were able, for

example, to make choices about what hosiery to wear, depending on the extent of the swelling and their activities on any particular day.

'I tend to monitor my leg daily... if I've had a late night I know it's going to be worse in the morning so now I know I've got various things I wear the next day'
(Participant 7)

Participants were asked specifically to describe how they would judge if treatment had been successful. Most described a reduction in the size of their limb and improvement in the shape as important markers of success. A reduction in infections and improved mobility, being able to wear shoes, and walking without a stick were also outlined as particular goals of treatment. Further measures of treatment success related to social functioning and aspects of self-image. These included getting a new job, going swimming with the family, playing a normal game of tennis, being able to walk around in a skirt, having fewer periods of depression and feeling more attractive.

Discussion

The study included people with various types of lymphoedema and highlighted the varied experiences of these different groups, allowing a number of early rec-

ommendations to be made (Table 4). Findings reflect a consistent lack of general awareness about lymphoedema that has also been reported elsewhere (Logan, 1995; Sitzia et al, 1998). Evidence from a survey of new referrals to 27 lymphoedema clinics in the UK showed that 65% of people with primary lymphoedema waited over 5 years for referral to a lymphoedema practitioner (Sitzia et al, 1998). The progressive nature of the condition is such that these individuals are more likely to present with a more severe and complicated lymphoedema. The impact of delayed diagnosis clearly has physical, psychological and emotional repercussions and seems to have a significant impact on the family, social and working life of many participants, a finding reflected in other studies (Moffatt et al, 2003).

Johansson et al (2003) also undertook interviews with 12 women with breast cancer-related lymphoedema and highlighted three similar themes: attitudes from people in their surroundings; discovery and understanding of oedema as a chronic disease and its treatment; and coping, including both problem-focused and emotion-focused strategies. Carter (1997) described how some women found the lymphoedema more distressing than coping with the cancer diagnosis, describing how they learned to adjust their lifestyle. This seems to corroborate the current findings and reflects the dynamic nature of coping (Lazarus, 1993). This suggests that health professionals need to acknowledge the different coping strategies of each individual in order to better support and empower people with lymphoedema.

The study reported here was small, focusing on the unique experience of particular individuals. The findings are therefore limited and cannot be generalized to other groups. The data were analysed and coded by one researcher, although rigorous coding techniques were used and two other researchers read the transcripts and contributed to the data analysis. Additionally, the opportunity to take the findings back to the participants for validation was not provided because of time restraints and therefore all stages of the phenomenological research process have not been completed.

The researcher had previously worked in the lymphoedema clinic and was known to the participants. This may have made it difficult for them to speak honestly about

Table 4. Recommendations

Education and information needs of people with lymphoedema	Further work into establishing the information and educational needs of people with different types of lymphoedema
Educational of health-care professionals	Assessment of the education and training needs of health-care professionals at all levels to enable early diagnosis and intervention and reduce the risks of complicated lymphoedema
Psychosocial and emotional needs	Increased insight into the psychosocial and emotional impact of lymphoedema and improved care in this area Development of appropriate tools to measure quality of life in these individuals and identify those requiring referral for psychological support Development of patient support groups to enable individuals to share experiences and expertise in self care.
Lymphoedema service provision	Development of appropriate resources and clinics for the treatment and ongoing support of people with lymphoedema
Treatment planning	Prior preparation (practical and psychological) for intensive treatment programme A collaborative approach to treatment planning and goal setting between the person with lymphoedema and the lymphoedema practitioner

their views, although it may also have enabled them to feel more comfortable about opening up and sharing their experiences. Indeed, allowing participants the opportunity to talk about their experiences appeared, from participants' comments, to be a very positive intervention in itself.

Conclusion

A large amount of data have been generated from this study and highlight a number of themes many of which warrant further exploration. In particular, the accounts of those with primary lymphoedema suggest that this group have specific difficulties that are not always fully recognized. Additionally, exploration of individual coping strategies may provide further insight into how people self-manage a chronic condition such as lymphoedema.

The experience of lymphoedema is unique to each person and health-care professionals should take time to explore psychosocial and emotional dimensions in those individuals with lymphoedema, as these will influence the success of the treatment plan. The need to develop information and educational resources for public and health professionals has been highlighted and recommendations are made for improving treatment and support for people with lymphoedema.



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Further information

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www.lymphoedema.org/lsn/

MLD UK
A professional association of Manual Lymphatic Drainage practitioners
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www.mlduk.org.uk

Key words

- Lymphoedema
- Primary lymphoedema
- Uncertainty
- Coping strategies

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