



Exploring patient perception of success and benefit in self-management of breast cancer-related arm lymphoedema



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ARTICLE INFO

Article history:

Received 13 April 2015

Accepted 3 August 2015

Keywords:

Lymphoedema
Breast cancer
Patient compliance
Treatment adherence
Qualitative research
Grounded theory
Self-management

ABSTRACT

Purpose: The aim of this study was to identify factors influencing patient perception of success and benefit with self-management of breast cancer-related lymphoedema (BCRL) and explore how patients decide whether their swollen limb has improved or deteriorated.

Methods: This qualitative study used a Grounded Theory approach. Twenty-one women in the BCRL self-management phase participated in one in-depth interview exploring their experience and perspective on self-managing their BCRL.

Findings: Seven enablers and blocks to self-management were identified: routine, recognising benefit of self-management and consequences of non-treatment, owning treatment, knowledge and understanding, problem-solving, time required for treatment and aesthetics of hosiery.

Women determined treatment outcome by monitoring size, appearance, texture and internal sensations within the affected arm.

Conclusions: Women who participated in this study showed varying degrees of acceptance and adjustment to life with lymphoedema. This appears to directly impact their ability to self-manage lymphoedema. Lymphoedema practitioners and oncology nurses have a valuable role providing knowledge and support to patients transitioning to independent self-care. A better understanding of factors facilitating patients to become experts in their condition may improve longer term outcomes and reduce cost pressures on lymphoedema services.

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1. Introduction

Lymphoedema is a common consequence of breast cancer treatment. It is conservatively estimated that around 20% of women undergoing axillary node dissection, and 6% undergoing sentinel node biopsy, will develop arm swelling at some point (DiSipio et al., 2013). The impact on the survivor is significant as breast cancer-related lymphoedema (BCRL) is not merely a physical problem of increased arm size and symptoms such as ache and heaviness, but

has many associated practical challenges related to daily living (Carter, 1997; Ridner, 2005; Fu, 2008; Radina, 2009; Ridner, 2009; Burkhardt et al., 2014). BCRL also causes considerable psychological distress as it alters body image and acts as a visible reminder of breast cancer and its treatment (Tobin et al., 1993; Curtis, 2006; Vassard et al., 2010; Fu et al., 2013).

Lymphoedema treatment generally comprises skin care, exercise, compression and manual lymphatic drainage (MLD). The initial intensive decongestive phase is followed by a maintenance phase of self-management (Lymphoedema Framework, 2006; International Society of Lymphology (2013)). The aim of treatment is to return the limb to as near normal as possible and prevent deterioration and development of complications such as skin thickening, fibrotic tissue changes, cellulitis, increased skin folds and hyperpigmentation (Lymphoedema Framework, 2006; Oremus

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et al., 2012; International Society of Lymphology (2013)). Life-long self-management is necessary to control lymphoedema as the underlying problem of reduced lymph drainage capacity cannot be rectified (Foldi and Foldi, 2012; International Society of Lymphology (2013)). In the UK, the self-management phase comprises compression armsleeves worn daily with a glove or gauntlet as appropriate, skin care, self lymphatic drainage massage (SLD) and exercise to promote lymphatic and venous return (Lymphoedema Framework, 2006).

Adherence to lymphoedema self-management activities is essential for achieving and maintaining successful treatment outcomes (Fu, 2005; Foldi and Foldi, 2012). However, there is no agreement regarding what constitutes a good treatment outcome. Poor adherence to recommended self-management may include neglecting aspects of self-management, such as insufficient use of compression garments, and failure to attend booked appointments. The little published information regarding adherence to BCRL self-management reports variation in adherence and compliance rates (Ridner et al., 2011; Jeffs and Wiseman, 2013; Brown et al., 2014). A better understanding of the issues surrounding patient adherence to lymphoedema management is needed.

Fu (2005) found that intention to engage in BCRL self-management was related to how women perceived lymphoedema, its consequences, and their ability to prevent deterioration of swelling and to accept and integrate treatment into their daily life. However, it is not known which factors most contribute to individual perception of improvement or deterioration in symptoms, or how women decide whether their treatment is effective. With increasing emphasis on assisting patients to self-manage their health (Davies and Batehup, 2011), there is a need to identify how patients monitor and perceive changes to their swollen limb, and how these perceptions relate to adherence to prescribed BCRL self-management.

The aim of this study was to explore improvement and deterioration in arm BCRL from the perspective of those affected by it, and to understand how these perceptions and other factors influence decisions to perform recommended lymphoedema self-management.

2. Method

2.1. Study design

A qualitative research design following Grounded Theory methodology was used (Corbin and Strauss, 2008). This systematic qualitative approach to data collection and analysis used the knowledge gained about living with and managing BCRL to move from descriptors of experience to developing a conceptual understanding of how women undertake and develop their approach to recommended BCRL self-management. Data collection entailed one off in-depth interviews exploring the experience and perspectives of women self-managing arm BCRL. It was envisaged the research approach adopted would generate clinically relevant findings to guide professional practice. Fig. 1 shows the flow of participants through the study.

2.2. Selection of participants

Participants were recruited from three lymphoedema clinics in London: two hospital-based and one hospice-based lymphoedema service. A sample of 25 participants was sought as it was believed this would be sufficient to reach data saturation, the point at which no new information is obtained (Corbin and Strauss, 2008). In accordance with principles of Grounded Theory, criteria for sample selection were refined as the study progressed in order to explore

emerging strands of interest and check findings across particular groups, for example, parents of young children, individuals from Black and Minority Ethnic groups, and individuals known to be struggling with lymphoedema self-management or non-adherent to treatment.

People eligible to participate in the study were men and women aged 18 years or older with arm BCRL, who had been in the self-management phase of BCRL treatment for a minimum 6 months. They were excluded if unable to communicate verbally unaided in English. Individuals with active disease were eligible for the study; none chose to participate.

One hundred eligible people at participating sites were approached by lymphoedema practitioners and informed about the study; they were given a study invitation letter, participant information sheet with contact details for the Researcher (EJ), and a stamped addressed envelope to return a form registering their interest in participating. Thirty three women responded to the invitation letter and were screened by the Researcher (Fig. 1); no men chose to participate.

2.3. Data collection

Interviews were conducted in a quiet room at participating sites ($n = 16$) or at the Researcher's hospital ($n = 5$). Participants were interviewed once for approximately 1 hour. Interviews were guided by a supporting interview schedule comprising a series of prompts regarding the experience of lymphoedema self-management, changes in BCRL symptoms, and perceptions of arm swelling.

Interviews were digitally audio-recorded and field notes written immediately following interviews to aid analysis. Interviews were transcribed semi-verbatim by a transcription service, leaving out background noises but including filler sounds (um, er), repetitions and descriptors (e.g. laughingly, pauses). Completed transcripts were checked for accuracy against the original recording by the Researcher (EJ).

Demographic and clinical data regarding severity of swelling and prescribed lymphoedema self-management were collected from participants' lymphoedema clinic notes by the Researcher (hospice only) or clinic staff.

2.4. Data analysis

Data collection and analysis ran concurrently incorporating constant comparison, a key component of Grounded Theory (Corbin and Strauss, 2008). Initial, and then more focused, coding broke data down into named component parts. These codes were grouped into larger subcategories and categories to formulate concepts which were discussed in subsequent interviews. Analysis of early data helped determine ongoing lines of questioning and the optimal individuals to recruit. The interview schedule was modified over time.

The Researcher (EJ) analysed transcribed interviews. Another research team member with expertise in Grounded Theory (TW) undertook early open coding and exploration of findings and supervised the analysis process. Summaries of emerging findings were circulated by email to the research team for discussion, leading to more detailed questioning of the data and further refinement of the analysis.

2.5. Ethical approval

Approval was obtained prior to commencement of recruitment from the National Research Ethics Service (NRES Committee London–Surrey Borders, reference: 12/LO/0930) and the Research and Development departments at each participating site.

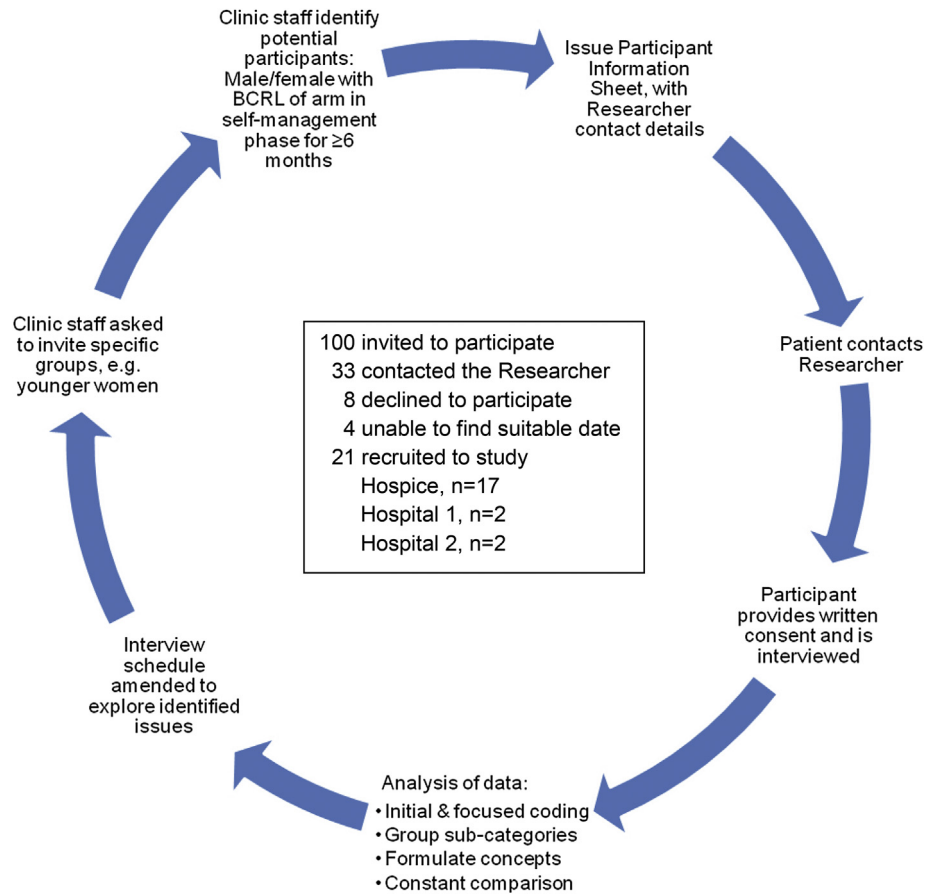


Fig. 1. Participant flow through study.

3. Findings

Twenty-one women were interviewed between 1st February 2013 and 30th November 2013. Most had arm lymphoedema of at least two years duration, which was considered by them and their lymphoedema practitioner (LP) to be mild-moderate in severity and stable. Participant characteristics are shown in Table 1.

3.1. Factors influencing the ability of women with BCRL to succeed in carrying out their self-management programme

The women all performed some recommended self-management, although activities undertaken and level of adherence varied (Table 1). They adapted their self-management programmes to suit personal goals and symptoms, compromising between the amount of self-management performed and severity of remaining swelling. For example, compression garments are noticeable so were not always worn in public or when swelling felt 'good', although were worn when symptoms worsened or to limit increased swelling following strenuous or repetitive activities. Some women felt guilty for not doing aspects of recommended self-care, whereas others appeared confident regarding their choice to adjust their self-management. Some believed further improvement with self-management activities was unlikely and used trial and error to determine the minimum effort required to maintain an acceptable level of swelling.

"I would say I wear it [the sleeve] 80% of the time, and I think I'm pretty good at doing that. Because I know what will happen if I

don't wear it. I leave it off if I'm going out or for whatever reason, but I wouldn't leave it off if I was lifting, if I was doing anything that involved putting pressure on it." (ID17)

The women's accounts suggest seven key factors that both positively and negatively influenced their ability to carry out self-management (Fig. 2).

3.1.1. Incorporating self-management into daily routine

Daily self-management was perceived as easier when part of an established routine where self-management activities were part of the fabric of everyday life rather than a focal point. Routine helped to normalise life with lymphoedema, and removed the need to think about it and its management. It also reduced the likelihood of forgetting to carry out aspects of self-management. In fact, achieving routine was seen by many as key to learning to live with lymphoedema and regaining a 'normal' life.

"Before I get dressed or anything else, I do the exercise and it's just part of my morning routine. And I think it's that routine-ness of it, you stop thinking about it, you just do it. And I think that makes life a lot easier" (ID13).

Women reported lack of routine as an influential reason why regular self-management was not done.

"Well, basically, I don't have a routine. It's just very on the moment. I suppose the answer would be a routine and it wouldn't be

Table 1
Participant characteristics.

ID	Age	Occupation ^a	Duration of BCRL ^b	Severity of BCRL ^b	Hosiery worn ^a	SLD ^a	Exercise ^a	Adherent to agreed self-care ^b
1	64	Retired	>3yrs	Mild	Daily	Daily	Sometimes	Yes
2	72	Retired	>12yrs	Mild – not a problem	Daily	When remembers		
3	76	Retired	>8yrs	moderate	Daily	Daily		
4	61	Translator	>4yrs	Moderate	Adjusts use	Daily	Daily	Yes
5	65	Retired	>2yrs	Mild	Daily	? Not done		Not sure
6	71	Retired	>6yrs	Mild, plus complex neuropathy	As pain allows	Yes	Daily	Difficulty with hosiery
7	71	Retired	>10yrs	Mild	Daily	Daily	Sometimes	Yes
8	47	District nurse	>4yrs	Moderate	Daily	Not done	Not done	Yes
9	61	Retired district nurse	>3yrs	Mild	Not always, not in hot weather	Yes		?
10	68	Retired	>4yrs	Moderate	Daily	Not sure	Yes	Not sure
11	65	Retired	18m	Severe	Daily	Not done		Yes (has carer)
12	82	Retired	>3yrs	Moderate	Daily	Daily	Sometimes	
13	65	Retired	18m	Moderate	No (with LP agreement)	Daily		Yes
14	54	Employed in retail	3yrs	Mild	Daily	Daily		Not sure
15	33	Admin, Self-employed	8m	Mild	Daily	Not done	Not done	Variable
16	33	Social researcher	2yrs	Mild	Daily	Daily	Daily	Yes
17	42	Full time mum	2yrs	Moderate	Daily	Daily		Yes (tho pt varies Rx)
18	62	Retired	8yrs	Severe	Daily	Occasional		Yes
19	52	General Practitioner	5yrs	Mild, bilateral	Daily	Daily	Daily	Yes
20	50	Clerical job	18m	Moderate	Little worn	Not done	Daily	No
21	57	Child minder	18m	Mild	Not worn	Not done	Daily	No

^a Reported by woman.

^b Reported by lymphoedema practitioner.

difficult, like cleaning your teeth, to do the massage if I could get that into my schedule” (ID2).

“If I've had a day where I've been on the computer a lot then my hand does swell up. But then I just sit and twiddle, exercising my fingers.” (ID20)

3.1.2. Recognising the benefit of treatment and consequences of non-treatment

Seeing and recognising the benefit of self-management activities was a motivator for continued daily self-management. Commonly reported benefits included reduced limb size, softer skin and tissues, improved appearance, and reduced ache/heaviness. A less commonly reported benefit was feeling secure and confident to control swelling.

“It doesn't hurt as much when I've got it [the sleeve] on ... it just feels more secure, it doesn't ache as much.” (ID17)

Some women noticed better control of swelling with regular daily self-care, particularly wearing hosiery. Others undertook self-management only when doing specific activities known to aggravate it, for example, hosiery was worn while shopping or doing household chores to prevent increased swelling.

“If I don't wear it [the sleeve] then I would notice it. I couldn't do my work without the sleeve because the sleeve is holding everything together.” (ID6)

Recognising deterioration in symptoms, such as increased size or ache/heaviness of the arm, often triggered an increase in, or commencement of, self-management. In addition, fear could be a strong motivator to undertake regular daily self-management to prevent deterioration of symptoms.

“If I've left the sleeve off then it'll build up and then I get the ache and the heaviness in the arm ... I do find a difference when I wear it [the sleeve].” (ID9)

“It's the need to survive – I'm the only bread winner and I've got to keep going [managing lymphoedema and being able to work] for me and for all the family.” (ID19)

Perception of treatment effect varied. Unchanged symptoms were viewed by one woman as a sign of successful symptom control and by another as lack of progress. Some women believed certain aspects of treatment made no difference to their swelling and were therefore a waste of time, so stopped that aspect of self-management.

“I haven't done any SLD. The massage was really, really, really boring, because the movements are so minute and exact and I

- Establishing daily routine
- Recognising benefit of self-management and consequences of non-treatment
- ‘Owning’ treatment
- Knowledge and understanding of lymphoedema and treatment
- Problem solving / dealing with the challenges of lymphoedema and treatment
- Time required for treatment

Fig. 2. Factors affecting ability to undertake lymphoedema self-management.

couldn't accept ... though you know the professionals that are saying it works, but I can't quite believe it because it feels like you're doing absolutely nothing." (ID15)

3.1.3. Ownership: choosing to undertake self-management

Women believed a positive attitude towards lymphoedema management, and a deliberate choice to undertake self-management for personal benefit, were important factors in the control of it. Many considered taking ownership of self-management to be linked to successful management of lymphoedema, whereas negative attitudes towards lymphoedema and self-management were linked with difficulty undertaking self-management activities.

"[It helps] that I've made myself realise that I've got a choice: I either wear it [the sleeve] and my arm will hopefully gradually go down even more, or I don't wear it and I end up not being able to do anything or I've damaged my arm because I get cellulitis" (ID18).

Rationalising the swelling seemed to help women to better accept their situation:

"At least I've not got it in my legs" (ID7,21)

"I've still got my life, so this is a small price to pay." (ID7,13,17,18).

"I just think it's much more important to get the ((sighing)) swelling under control and get the thing functioning properly than what it looks like (...) I think as you get older you just realise that everyone's got something or other they're dealing with ... issues, illnesses, conditions, that they're just living with, so that's just kind of the way it is." (ID16)

Some women described reaching a point where lymphoedema was an integral part of who they were, with self-management so much part of normal daily routine that it was no longer consciously planned. They referred to this as living normally, a 'new normal'. As they talked about their experiences, several women realised they had gained control of lymphoedema and were no longer controlled by their self-management activities. They desired that all women with lymphoedema would discover it was possible to enjoy life following breast cancer treatment.

"I just try and live as normal as possible, but obviously it's like restrictions. It's not going to run my life. It's not going to be one of those things you say I can't do that because I've got lymphoedema ... It's [the sleeve's] part of my everyday life now. It's just there and you just do it." (ID1)

"I've sort of hit a point where I'm stable, and then I had my wedding ring and engagement ring increased. That took four years but now I'm able to wear my rings all the time now (...) I suppose knowing that you've got to live with it, but it's a forever, ever and ever thing isn't it. (...) I think something clicked in the brain ... got to accept it first, then tackle it and then get the results." (ID7)

Not all women felt they had fully accepted lymphoedema and its treatment, or were ready to do so. Some women considered only hands-on therapy or monitoring of swelling by the LP to be treatment and did not recognise self-management (particularly hosiery) as lymphoedema treatment.

"I have been coming here ... mainly just to measure up to see how bad it was and then measure me up for a sleeve and glove and that

... Well the treatment is mainly just to see how, whether it's gone up or down really." (ID10)

Regular exercise was used by some women to specifically gain a sense of well-being and control of swelling, because they could exercise whenever they had time or felt the need for additional attention to their swelling.

"My routine in the shower is doing all my exercises first thing in the morning. If I see that down here ((points to hand/wrist)) is more swollen than usual, then I will do more exercises. And I know that if I do more exercising with it, maybe twice or three times a day, it does go down." (ID21)

3.1.4. Knowledge and understanding

Knowledge about lymphoedema and its treatment was considered essential for successful self-management, with three areas deemed important for quickly becoming proficient in both self-management and long-term control of swelling:

- i) recognising the value of treatment to help reduce and control swelling,
- ii) "listening to your body" and recognising the range of fluctuation in swelling,
- iii) adjusting self-management activities to control symptoms.

The women highly valued access to the LP as a knowledge-giver and problem-solver. Information was also obtained from the Lymphoedema Support Network, internet and newspaper/magazines. Tips and advice regarding practicalities of self-management were particularly valued, whether from the LP or other people with lymphoedema. Fig. 3 summarises the tips and advice women believed should be given to people early in their lymphoedema journey.

Lack of knowledge and understanding was frustrating and unhelpful. Women who struggled with treatment techniques were often too embarrassed to admit they could not learn or remember treatment skills, and reluctant to ask busy LPs for more skills training.

"I'm not a dunce but I just find it very difficult to follow a sheet [instructions]. I'm more practical. I prefer someone to show me, and she has shown me but only once and I can't, I didn't take it in. (...) I'm going to have to be shown again but it's me having to ask her really, and she's so busy." (ID5)

Regular reviews of progress, with support from the LP to know when and how to adjust treatment, helped motivate and encourage continuation with self-management.

"When I came back and she said 'There's no change from last year, you're the same ... Whoopee, it's a wonderful feeling where you think well I, I've done well then, I've kept that down. That's a whole year. So, you know, it gives you a little bit of a kick doesn't it.'" (ID7)

Some women found it challenging to be discharged from the clinic as they lacked confidence to monitor their swelling.

"I've been thrown out. The last time I came nurse measured my arm and said it's been the same now, so we don't need to see you unless you have a problem. It's such an insidious progress, would I spot it in time? I don't know. I'm not awfully confident because I don't want to get a fat arm and it was like a safety net - periodically I'd

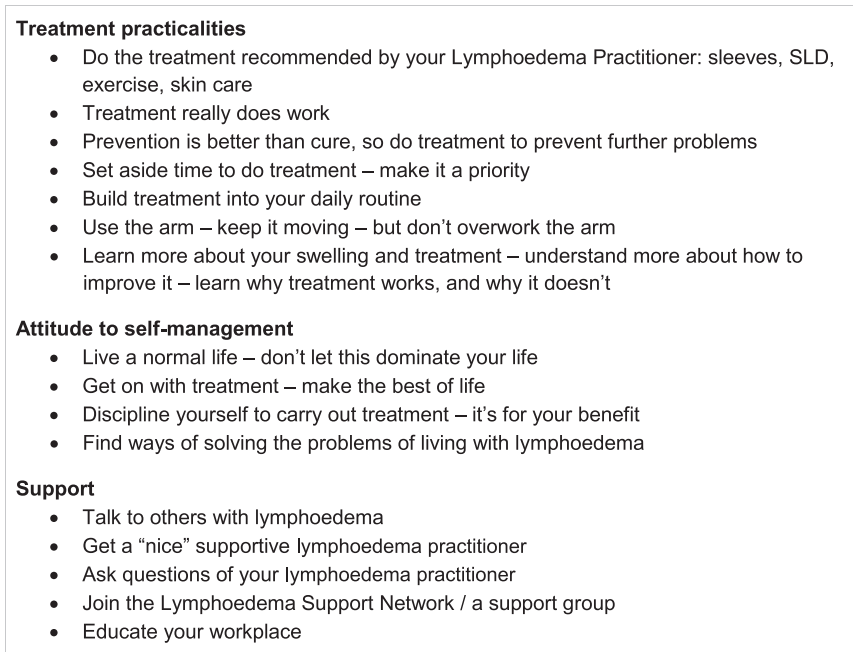


Fig. 3. Advice I would give to other patients regarding things I wished I'd known when starting out my lymphoedema journey.

have my arm measured and everything was fine, that was good. (...) I may not notice it but a tape measure would." (ID2)

Women valued meeting other people with lymphoedema who shared their experiences and understood their problems, although only a few belonged to a support group. They believed it would be helpful to have advice early in their lymphoedema journey from other people with lymphoedema, to encourage continuation with treatment. Perceived benefits included gained perspective regarding their swelling and using their experiences to help others.

"There was a lot of support, a lot of friendship there, and I saw what others had to contend with and it was more than what I had (...) There was ladies over there in tears because they were going on holiday and they didn't know what to do with the arm and I said, 'You wear your sleeve in the day. You can still sit out on the lounge on deck but put a lovely, colourful towel over it ... and when you go down in the evening, just get a nice little shuzzy scarf, you know, just slip it underneath your strap of your evening dress, it covers the arm.' " (ID7)

Family member support was important for providing encouragement and motivation to continue self-management. Several women suggested that individuals without family support may have greater difficulty undertaking self-management and coming to terms with their condition.

3.1.5. Problem-solving

Problem-solving was viewed as essential to taking ownership of, and becoming skilful in, lymphoedema self-management. Women described many examples of finding practical solutions to the problem of living with lymphoedema, including adjustments to home and work environment, use of clothes and colours to disguise hosiery and swelling, establishment of routines to facilitate self-management activities (e.g. planning exercise as part of the morning routine), and treatment combined with other activities (e.g. SLD done while watching TV).

"Alright, putting on the sleeve I must admit you do have to wrestle and I imagine for an older person, they would need help. But now I've got technique, and I've learned to get a little a cushion and put it by the side [of my face] and hold and pull up [the sleeve] so that I don't punch myself in the face ((laughs))." (ID1)

"I say to [my patients], 'show me how can you lift your arm up', and I will always take the opportunity to lift this arm up and say, 'can you lift it up like this? Show me.' So, I've done my exercise and I've got someone else [to do] what I wanted." (ID19)

Hosiery created more challenges than any other treatment activity, although was generally viewed as beneficial. Some women experienced greater physical and psychological difficulty with hosiery than others. Arm garments were disguised by clothing but hand compression garments were highly visible and also restricted function affecting a wide range of activities, including various household chores, writing and hygiene. Women found it particularly unpleasant to wear the same garment for clean and dirty tasks (greeting people, toileting, cooking, eating). They commonly removed gloves and hand-pieces, and forgot or chose not to replace them when the activity was ended, which often led to increased hand swelling. Women proposed hosiery provision be increased from two to four items every 6 months.

"Well the gloves ... they do get quite dirty and frayed and things like that ... I don't know if they can just give you a couple more ... you know, 2 sleeves are fine but if we could have 4 gloves instead of just the two." (ID1)

"It restricts your movement a bit and just gets in the way of everything, of daily activity ... because you're wearing it all the time, but then it doesn't feel very hygienic if you take food out the fridge or obviously go to the bathroom. You take it off to go to the bathroom." (ID15)

Hosiery problems also included discomfort from friction and tightness of garments, particularly during hot weather, visibility of

hosiery, variation in quality and size of garments, slippage of garments. Women sought ways to tolerate hosiery, including disguising it, although some removed hosiery if uncomfortable or never wore it.

"[The sleeve] is so tight ... it cuts right in tight ... I rip it off." (ID6)

"I wear the sleeve every time I'm working, I just keep my cardigan on all the time." (ID8)

"That [sleeve] was so uncomfortable and it just kept on rolling down more and more (...) and I must have, I think, tried four different ones and, you know, they don't stay on ... It makes it hard to use, yes. It makes me non-compliant with it ... If I'm going to be in public, I can't keep putting my hand down my neckline and pulling the thing up." (ID19)

There was widespread agreement that the colour, appearance and comfort of hosiery need improvement, although views differed regarding the optimal colour.

"These gloves aren't the most fashionable, and they're not the most elegant of things. And they can never match up the two colours [of sleeve and glove], so it's very obvious you're wearing them. Come summer months, when it's hot, and you want to put summer dresses on, you stand out like a sore thumb." (ID1)

3.1.6. Time required for treatment

Time pressures and juggling competing priorities were limiting factors for self-management, particularly for women with children and those in full-time employment. Self-management elements perceived as easy or providing particular benefit were prioritised. Compression hosiery was considered the quickest and easiest treatment, as hosiery was generally applied only once per day. SLD and exercise were popular although they required more time. Some women found SLD simple and easy to do, even combining it with rest time or watching television, whereas others struggled to find time to undertake 10–15 min massage particularly if they had young children or a busy job, or had difficulty remembering the correct technique.

"The sleeve is really quick to put on so it's not taking a lot of time, whereas the massage is what 10–15 minutes time that you would have to take from something else." (ID15)

"I'm struggling to find time to do it [my body massage] because I do full time job and I've got two teenage children, is like all hands on all the time." (ID8)

"If a little bit of time spent on SLD and some exercises for my arm will enable me to keep doing as much as I can for as long as I can - I mean I'm now retired - what's a bit of inconvenience?" (ID13)

It takes time to learn to get on with life, to reach the point of accepting lymphoedema and embracing necessary self-management activities to control swelling. Initially, overwhelmed by all that was entailed in learning to manage lymphoedema, the women found different ways of coping with their changing life, swinging from hope the swelling would completely resolve to despair that life would never again be normal. Much of life was lived in the middle of these two extremes. At times, treatment was abandoned or carried out obsessively to the point that lymphoedema self-management dictated other aspects of life and family activities. Mostly, women adjusted the type or amount of daily self-

management according to their perceived symptoms or demands of daily life. They gradually learned to listen to their body, recognised changes to symptoms, and decided when to use or adjust self-management activities to bring their swelling under control.

"I would say my treatment, what I was doing, was quite intense because I was almost fanatical about it...you tend to think it runs your life (...) it was getting in the way at first, you know, I was quite uptight about it at first. (...) [now] I've got mine under control so well that if I wear the sleeve all day busying about the house or whatever then when it comes to my turn to enjoy myself the sleeve comes off, just for a couple of hours or overnight." (ID7)

Some women believed there were insufficient appointments for consultations or treatment (e.g. MLD). They viewed LPs as very busy and were reluctant to bother them. One woman compared the resources of the breast care and lymphoedema services at her hospital, observing that the lymphoedema service lacked adequate resources which impacted on patient care.

"... the breast cancer nurses, there's more of them I think per patient, and they have quite a slick system, you know, where you can get through to them and you get a call back that day, or at least you did when I was having my treatment. And I don't think it's comparable for the lymphoedema [clinic], and I'm sure that's because the same resources aren't put into it so ... you're supported but you're not as brilliantly supported as I'd say I was through breast cancer treatment." (ID16)

3.1.7. Aesthetics of hosiery

One unintended consequence of treatment is that hosiery is visible, particularly hand garments, and therefore reveals the presence of lymphoedema. Women were frustrated at having to explain about lymphoedema, and felt uncomfortable revealing in public they had had breast cancer. They tried to avoid questions, but felt the need to prepare a story to answer in case.

"... people keep asking you 'Oh what happened to your arm?' I don't want to be telling a whole lot of story ... even my patients, they all say 'What happened to your arm? What happened to your arm?' I smile and says 'Oh it's nothing, just a support'. I don't want to be telling stories, so I just find something to say." (ID8)

Some women believed their swelling was only noticeable to others when compression garments were worn, which influenced their decision when to wear hosiery.

"A lot of people like look and it's like, 'Oh, oh, what's the matter with your arm?' ... So just going round the school, because not everyone knows, I might consciously think, I'll put that [the sleeve] on after because I can't be bothered to explain (...) So many people, 'oh, what have you done to your arm?' ... Oh my, explaining all the time. (...) Yesterday I think three people asked me just generally, 'Oh, what have you done to your arm?' One chap in the dentist's surgery, just sitting there. A lady in the supermarket, on the checkout. Two people, I think, in the supermarket." (ID17)

A few women felt hosiery acted as a reminder of cancer.

"I felt I wasn't going forward. I felt it [the sleeve] kept reminding me of the cancer and ... I was protecting the arm with not getting on with my life." (ID9)

Size	fit of clothes, jewellery, use other hand to gauge size of swollen area
Appearance:	look for presence of anatomical landmarks, veins, and muscle definition
Texture:	feel the consistency of swollen area, whether firm, hard or soft
Internal sensation:	most commonly a sense of fullness, ache or heaviness

Fig. 4. Determining outcome of treatment.

3.2. Determining the outcome of treatment: how does the individual decide whether their swelling has improved or deteriorated?

Women could not immediately articulate how they decided whether treatment was effective, or how they knew if swelling had changed. Many considered clinical measurements taken by the LP were the most accurate way of monitoring swelling, although some observed that the impact of swelling was not necessarily related to changes in objective measurements.

“When I’ve come and told the nurse here I think my arm is quite swollen she measures it up ... and will say, ‘Oh, it’s only about 30 or 50 mls difference in volume.’ ... if you measure it in a glass of water, [that] is pretty small ... but the impact I think is way more than what the volume states.” (ID19)

By describing the difference between their swelling on a good and a bad day, they identified four aspects they regularly monitored: size, appearance, internal sensations, and the feel or consistency of their swollen limb (Fig. 4).

Women commonly monitored limb size by fit of clothes or jewellery and by visual comparison with the unaffected limb. A rough estimation of size was quickly and easily obtained by circling fingers and thumb around the narrowest part of each wrist, compared with their memory of previous days. Some women used particular items of clothing or jewellery to test whether their

swollen limb had significantly altered size.

The visibility of anatomical landmarks, particularly knuckles and veins on hand and wrist, was another quick and easy way for women to monitor change. Some women checked the appearance of their forearm, using wrist rotation and elbow-flexion to observe forearm muscle definition; muscle movement was more clearly visible on good days, but may be obscured by increased swelling.

The quality of skin and tissues was judged by gently pressing fingers and/or thumb over the swollen area. Commonly, women used words such as ‘soft’ or ‘normal’ to indicate good days when the limb was less swollen, while ‘fat’, ‘tense’, and ‘hard’ were used to indicate worse swelling. These are relative terms, and it appears likely a sustained change in swelling severity may alter a woman’s personal reference point.

Common terms used to describe swelling on a bad day included: feeling of fullness; internal pressure, tension, tightness; ache or heaviness deep inside the arm. Some women struggled to describe changes felt within their arm, merely stating their arm “feels different” (ID2) or “doesn’t feel right” (ID17). Internal symptoms appeared to be triggered by certain activities, such as household chores, writing or computer work, and may be related to an awareness of having done too much activity. Sometimes, women adjusted self-management specifically to ease internal sensations, for example, increased time wearing hosiery.

One woman (ID16) suggested a progression to symptoms associated with increased swelling: first, an awareness of internal sensations (fullness, then ache or heaviness in the arm), then

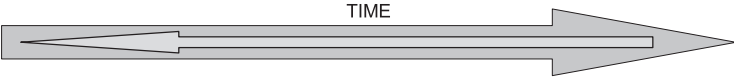
		TIME 					Living with lymphoedema integrated with normal life
Emotions	Feel overwhelmed	Anger/denial	Resentment Reluctance	Resignation	Acceptance	? embrace new life – create new normal	Ownership. Achieve new normal
	Feel out of control	Fight for control – control fluctuates		Gain control		Maintain control	Feel in control & able to deal with any changes
Actions	Learn to do self care Follow instructions	Ignore instructions – refuse to do self-care Fluctuate between fanatical and laissez-faire attitude to self-care		Choose to do self care Find practical solutions	Build routine Plan for success	Take control of treatment programme & self-monitoring	Able to flex treatment to deal with fluctuation in symptoms, and to mesh with personal goals
	Lymphoedema practitioner	Dependent on LP	LP monitors swelling, adjusts treatment		LP input reduces Gain independence and confidence in own skills	Can feel abandoned by LP, as appts reduce	Self-reliant. Monitor own swelling & adjust treatment
Knowledge required	Learning about lymphoedema & self-care: what, how, why, where, when	Solutions to problems Rationale for treatment Recognising changes to symptoms		How does treatment work? How can I do this better/easier? How to find solutions to challenges Learn to monitor own progress Consequences of non-treatment	How to adapt treatment to symptoms & circumstances	Become expert patient	

Fig. 5. Transition from novice to expert – adjusting to living with lymphoedema.

changes to the tissues and, if remedial action not taken, increased hand size and loss of definition of knuckles and veins evident by the end of the day. She had noticed that increased hand swelling was more likely to occur on days when she was busy and did not pay attention to the onset of internal symptoms. She believed these internal sensations were an early warning sign and that, by paying attention and taking early action (extra exercise or SLD), she could avoid exacerbation of swelling.

4. Discussion

The findings of this study are summarised in Fig. 5. They add to the growing body of knowledge regarding the physical, mental and emotional challenges of living with lymphoedema (Ridner et al., 2012b; Fu and Kang, 2013; Fu et al., 2013), and provide new insight regarding the process of coming to terms with lymphoedema and life-long self-management. The journey from novice to expert, to someone who is confident and competent in managing their own condition and in control of their life with lymphoedema, takes time. The transition involves emotions, knowledge, practical skills, and choices around treatment as women learn to accept a life with lymphoedema (Fig. 5).

Perceived treatment benefit is considered an enabler for self-management (Fu, 2005; Ridner, 2009; Karlsson et al., 2014), however, our findings suggest that the same treatment outcome can be perceived differently (positively or negatively) by different women and this has implications for adherence to self-management. There is little information regarding what women can expect from self-management of lymphoedema, and the consequences of treatment choices may not immediately be seen. Attitudes and beliefs about treatment have a greater impact on self-management behaviour than factors relating to the complexity or impact of treatment (Fu, 2005; Jin et al., 2008; Meiklejohn et al., 2013). The women compared perceived severity of swelling with personal cost and benefit of self-care and made adjustments to self-management, although their choices sometimes ran counter to professional opinion regarding the best approach to managing lymphoedema. For example, some women removed their compression glove or pulled back the hand-piece over the wrist while carrying out wet/kitchen work without considering the impact on hand swelling.

Knowledge impacts ability to carry out self-management activity, and a lack of knowledge about the mechanism of treatment and expected outcomes will inevitably affect perceived benefit of treatment. Lymphoedema education to date has focused on advice to women at risk of developing lymphoedema and practical aspects of treatment, with little mention of expected treatment outcomes or how to monitor symptoms (e.g. (Ridner et al., 2011; Armer et al., 2013)). Our findings suggest different types of knowledge are required at different stages of the lymphoedema journey (Fig. 5). For example, the novice patient needs information about how and why to do treatment. Once the basic concepts of lymphoedema management are gained, knowing how to recognise and interpret symptom changes and adjust treatment accordingly is more beneficial.

Public visibility of lymphoedema is a concern for many women (Fu and Rosedale, 2009; Meiklejohn et al., 2013). The findings of this study suggest that for many women it is hosiery rather than swelling itself that exposes lymphoedema to others. This is likely to impact treatment adherence (Karlsson et al., 2014). As more women present earlier and with minimal swelling (Dayes et al., 2008), they may decide not to wear hosiery in public to avoid revealing their history of breast cancer. Greater effort is required to normalise the appearance of hosiery, exploring advances in textile technology and advising women regarding ways to disguise hosiery and therefore lymphoedema.

Various studies have reported the yearning women experience for a return to normality, specifically pre-lymphoedema normality, whilst questioning whether this can ever be regained (Ridner et al., 2012a; Fu and Kang, 2013). Our findings suggest that, although loss of pre-lymphoedema normality is an inevitable part of the experience of living with lymphoedema, women can create a new normal where life is not controlled by lymphoedema and demands of treatment.

The growing body of literature regarding factors influencing adherence to lymphoedema self-management and therapeutic compliance in managing chronic conditions, suggest links with methods of coping, for example, accepting responsibility, escape-avoidance, planful problem solving (Folkman and Lazarus, 1988; Rogers et al., 2007; Jin et al., 2008; Fu and Kang, 2013; Meiklejohn et al., 2013; Thompson, 2014). Jin et al. (2008) suggest the interaction between factors affecting treatment compliance acts both synergistically and antagonistically. By incorporating self-management activities into the everyday routine of life, the psychological burden of treatment is reduced (Fu, 2005; Meiklejohn et al., 2013). The regular application of treatment increases the likelihood of seeing treatment benefit, another recognised enabler for self-management, and strengthens a sense of control over lymphoedema (Fu, 2005; Ridner, 2009; Meiklejohn et al., 2013). Our findings suggest that routine is not only key to learning to live comfortably with lymphoedema but also for gaining a new sense of normal, as has been found in other chronic conditions (Fu, 2005; Rogers et al., 2007; Meiklejohn et al., 2013; Thompson, 2014).

Monitoring of treatment outcomes is typically focused on objective measurement of physical symptoms, psychosocial and functional issues including quality of life (Fu et al., 2013; Pusic et al., 2013; Davies et al., 2014; Perdomo et al., 2014). These aspects do not necessarily indicate whether the patient considers their swelling to have improved. Our findings show that the women do monitor their clinical symptoms but are not necessarily confident to monitor and interpret changes over time. Interestingly, their assessment criteria of size, appearance, texture and internal sensations largely mirror the clinicians' routine assessment of decreased visibility of veins, increased thickness of the skin and subcutis, fullness of the tissues or smoothing of natural limb contours, and pitting oedema (Stanton et al., 2006). Patient reports of physical symptoms have been used to assess levels of distress, compare perceived degree of swelling with objective limb volume measurements, and determine presence of swelling (Norman et al., 2001; Armer et al., 2003; Czerniec et al., 2010; Ridner et al., 2012a, 2012b; Fu and Kang, 2013). Aspects of the clinician's routine assessment (Stanton et al., 2006) are included in self-report diagnostic tools (e.g. (Norman et al., 2001; Armer et al., 2003)) but there is a lack of tools to support patient judgement of swelling improvement. Educating patients regarding the range of symptoms to monitor, likely progression, and potential for early intervention to avert the development of visible changes, should improve control of swelling, which may improve adherence to self-management activities.

5. Strengths and limitations

Qualitative research generates deep and rich findings as they are ground in, and often illustrated by, patients' voices (Kuper et al., 2008; Morse, 2012). However, participants in this study are not necessarily representative of the BCRL population as a whole, and therefore the findings should be interpreted with caution (Polit and Beck, 2010). The participants were all women, mostly white British retirees from predominantly one study site in south east London (UK). They were considered by their lymphoedema practitioner to have mild-moderate severity lymphoedema and be generally

adherent to self-care. No men were recruited. Individuals known to be struggling or non-adherent to treatment proved difficult to recruit; they may have been more willing to complete a questionnaire or join a focus group specifically exploring the problems of treatment.

These findings relate to the self-management phase of treatment in the UK, and may therefore have limited relevance in countries where practice differs and for individuals undergoing intensive therapist-led treatment.

6. Implications for practice and relevance to oncology nursing in Europe

Lymphoedema practitioners are clearly influential in the journey from novice to expert lymphoedema patient and have a key role in educating and equipping the patient to become expert in self-management. Treatment pathways should support movement from novice to expert patient, with explicit indications for discharge, enabling patients to independently identify and address deterioration in symptoms and make sense of treatment outcomes. This could halt the progression of lymphoedema and facilitate fewer treatment appointments, thus reducing health care costs.

Patient education should include realistic expectations of treatment, how to identify personal treatment goals, monitor symptom changes, and adjust self-management accordingly (Fig. 5). Hosiery and other self-management activities should be explicitly promoted as lymphoedema treatment to encourage active self-management and adherence to treatment. Techniques such as motivational interviewing may help the patient explore and resolve any ambivalence regarding self-management (Emmons and Rollnick, 2001). Oncology nurses have a key role in patient education and psychosocial care of patients, and are in an ideal position to reinforce the importance of treatment adherence and identify women struggling to come to terms with BCRL and life-long self-management.

Developing an expert lymphoedema patient buddy system would allow women to support fellow patients starting on their lymphoedema journey and those struggling with the transition to acceptance of it. Social networks for health may benefit women with BCRL, such as healthunlocked.com and the Lymphoedema Support Network community.

LPs and oncology/breast care nurses should champion provision of adequate hosiery, particularly hand garments. Provision of additional garments should improve treatment adherence, and thus overall control of swelling, with long term cost savings by avoiding unnecessary additional treatment costs associated with failure to wear hosiery and deterioration of swelling.

7. Recommendations for future research

Further research is needed to better understand the process of coming to terms with lymphoedema, impact of ownership, perception of treatment benefit, and the role of the LP in facilitating the transition to expert patient. Focus groups could be used to explore how the findings of this study relate to other cancer groups with lymphoedema and to the small number of men with BCRL.

Research is also needed to determine how informational needs change over time, and the optimal focus and timing of education at different stages in the lymphoedema journey. Further work is required to determine the role of peer support, and whether suggested additional information and support (Fig. 3) is relevant to the whole BCRL population.

There is need for tools to be developed to help patients confidently monitor their swelling (size, appearance, texture and

internal sensations) and indicate when to take action to minimise symptom changes.

8. Conclusion

The women who participated in this study showed varying degrees of acceptance and adjustment to life with lymphoedema. This appeared to directly impact their ability to self-manage lymphoedema. Lymphoedema practitioners and oncology nurses have a valuable role providing knowledge and support for patients transitioning to independent self-care. A better understanding of the factors facilitating patients to become experts in their condition may improve longer term outcomes and reduce cost pressures on lymphoedema services.

Acknowledgements

This research was funded by an European Oncology Nursing Society (EONS) Major Research Grant in 2011 and supported by Guy's & St Thomas' NHS Foundation Trust. EONS had no involvement in the study design; the collection, analysis and interpretation of data management; in the writing of the report.

We would like to thank the women who participated and provided their stories and insights into living with lymphoedema, and also the staff at the lymphoedema clinics of Greenwich & Bexley Community Hospice, St George's Hospital, Tooting, and University College Hospital, London.

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