

**Title:** 'Experiences of breast cancer related lymphoedema and the use of reflexology for managing swelling: a qualitative study.'

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**Abstract:**

*Background and Purpose:* An estimated 1 in 5 women surviving breast cancer will go on to develop breast cancer related lymphoedema (BCRL). There is a gap in the literature capturing experiences of people living with BCRL who use complementary therapies.

*Materials and Methods:* Data were collected from 26 participants via a semi-structured interview. Questioning centred around their personal experiences of living with lymphoedema, and their use of reflexology lymphatic drainage.

*Results:* Four main themes emerged which comprised physical and psycho-social impacts of lymphoedema, experiences of physical change, and the return of optimism. RLD treatment was considered pleasant and non invasive, and the reduction in swelling helped with pain and mobility.

*Conclusion:* The main conclusion from this qualitative evaluation was that participants perceived benefit on physical and psychological levels. Participation in the study appeared to help re-engagement with normal life. Further research is needed to quantify the changes in these parameters.

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## **1. Introduction**

### **1.1 Breast-cancer related lymphoedema (BCRL)**

Treatment for breast cancer is one of the main causes of secondary lymphoedema of the upper limb in the developed world [1]. It occurs when surgery or radiotherapy cause damage to lymph vessels or nodes in and around the axilla. There follows an interruption in the transport of interstitial fluid which accumulates in the tissue spaces causing swelling of the limb [1].

Breast cancer is the most common cancer in women in the UK, with 31% expected to develop it in their lifetime[2] . It is estimated that 1 in 5 women surviving breast cancer will develop arm lymphoedema, although estimates vary particularly with the extent of surgical treatment and body mass index [3, 4]. As survival rates improve, the prevalence of BCRL is likely to increase [3]. The condition is distressing and disfiguring and its development is associated with diminished strength, fatigue, and pain in the affected arm along with impaired functional ability, loss of confidence, and poorer emotional wellbeing [5-7] .

Whilst BCRL remains an incurable condition there are a range of multi-disciplinary approaches which are thought to provide some symptomatic relief [8, 9]. There is broad agreement that a holistic approach is needed [1].

Most commonly used in prevention and reduction in lymphoedema volume is the use of compression bandages and compression garments [10, 11] but there is a gap in the literature about psychological effects and adherence to this treatment. Too little physical activity is considered a risk factor in the development of lymphoedema [3], however increased exercise is recommended and considered safe in this patient group [12, 13]. Exercise has the additional benefit of contributing to improvements in physical fitness, functioning and quality of life. There is some suggestion that it may also reduce lymphoedema in the arm [14]. There is also evidence to suggest that healthy eating can contribute to volume reduction in BCRL.[15]

Manual lymphatic drainage is a light form of massage used to move retained lymphatic fluid from the arm and into an undamaged area in the upper torso. Current evidence does not support the use of manual lymphatic drainage (MLD) as a stand-alone intervention for

preventing or treating BCRL [16]. However there is a suggestion that MLD in combination with other interventions, such as compression therapy may help to reduce arm volume [10].

There is a need for more qualitative research capturing personal experiences of living with BCRL, and of the treatment interventions for managing it. This study emerged from a convenience sample of BCRL patients who were involved in a feasibility study looking at a lymphatic drainage protocol of reflexology which targeted arm swelling.

## **1.2 Reflexology**

Reflexology is one of the most commonly used forms of complementary healthcare [17, 18], and one of the most often used by patients with cancer [19]. A therapeutic modality based on the theory that discrete areas of the body may be mapped onto the feet, a standard reflexology treatment typically involves applying pressure to specific areas on the feet using thumb, finger and hand techniques [20]. This pressure is thought to invoke a relaxation effect, improve blood flow and facilitate a rebalancing of physiological processes [20]. During a reflexology treatment tenderness felt in foot reflexes recedes after which a corresponding reduction in physical symptoms in the body is said to occur [21].

There is some evidence that reflexology may benefit the physical and emotional symptoms of patients with cancer [22-27], although more high quality research is needed [28].

Reflexology is reported to have positive benefits in palliative care populations, it is considered non- invasive, pleasant and relaxing [29]. Explorations into physiological responses after foot reflex activation have suggested that a more targeted reflexology approach might have something to offer specific conditions or pathologies. [30]. Reflexology lymphatic drainage (RLD) is a protocol which activates lymphatic zones on the feet in a precise order, with the aim of working with lymphatic and renal systems through identified areas on the feet. Working with the theoretical basis that each area of the body has a corresponding point on the foot, this targeted protocol was developed by matching the pattern of movement used in MLD (Manual Lymphatic Drainage). The main differences are that the corresponding reflex areas of the feet are activated instead of working directly on the arm, shoulder and chest. The reflexology lymphatic drainage protocol was considered to be a less invasive option than MLD which often requires direct contact over the surgical areas. Reflexology lymphatic drainage (RLD) is tailored specifically to the patient in that the site of surgery dictates where on the foot reflexes the protocol begins. Anecdotally this type of reflexology is reported to have a more immediate and long lasting effect than standard reflexology which seeks to relax the whole body. This research was developed in response to the need for further exploration of these reported effects. Quantitative measurement data

were reported in another paper [31]. Briefly, the 26 women involved were measured for arm volumes and compared over a period of 7 weeks. Four reflexology lymphatic drainage treatments were administered weekly. All 26 women completed the study and all of them were found to have lost excess arm volume over that period, typically of around third. Time with the condition did not affect the resulting fluid loss, suggesting this intervention is useful even after some years had passed. Here we present the patients' experiences of the use of RLD in managing their BCRL.

### **1.3 Aims**

The aim of this qualitative data capture was to explore the psychological impact of BCRL on daily life, and how the use of reflexology for lymphatic drainage affected them.

## **2. Method**

### **2.1 Sample**

Data were collected from 26 subjects from three discrete areas of South Wales. Tredegar (n=5), Bridgend (n=6) and Cardiff (n=15) between February and April 2014. All of the participants had undergone surgery for breast cancer, which included the removal of axillary lymph nodes, and all had developed secondary lymphoedema in one arm.

### **2.2 Semi-structured Interview**

A semi structured interview was conducted at the end of the 7 week study to capture experiential data from the participants.

The development of the interview schedule was conducted via a research advisory group which included people from the community recruited by the Tenovus cancer care charity, research team members and representatives from each of the three research locations.

Those with experience of BCRL were asked what areas of questioning they felt was most relevant for the study. Those with experience of treating breast cancer patients were also asked what they felt was most relevant. Discussions resulted in four areas of questioning being decided upon:

- How lymphoedema affected them prior to the start of the study;
- Experiences or reactions during the reflexology lymphatic drainage procedure;
- How they felt about their lymphoedema after the end of the trial;
- Any other comments they would like to add.

Interviews were conducted at the seventh week at each of the three sites by the research associate. Recorded interviews were then transcribed verbatim into Microsoft Word for Windows © (version 7) for further analysis.

### **2.3 Interview data analysis**

An inductive category development method of qualitative content analysis was used. Qualitative content analysis is defined as a research method for the subjective interpretation of textual data through a process of systematic classification. It is a method of analysing transcribed verbal data such that the narrative can be separated into categories, or themes and these further analysed for explicit or inferred meaning [32].

The transcribed interviews were imported into QSR NVIVO (version 10), a software tool for the analysis of qualitative data. The first stage of data analysis involved two researchers reading all transcripts as a whole, in order to immerse themselves in the dataset. The second pass through the data consisted of data coding using QSR NVIVO (version 10), at which stage initial categories were identified from the data.

Inductive content analysis was performed by two researchers, first independently and then together. Each researcher brought a different perspective to the data analysis. One was an academic and reflexologist, the other was a professional researcher with no reflexology experience. With a view to establishing clear communication between them, reflective questions about their perspectives on the data were discussed [33] as recommended by in order to establish an analytical framework.

Each researcher performed an initial coding process using QSR NVIVO to provide a basic parent/child hierarchy of categories. These initial categories were modelled into diagrammatic representations to facilitate ease of clustering. Then the two researchers came together and discussed their findings to establish where patterns of similarity occurred. Discussion about the categories identified led to further refinement of the structure by developing a series of 'category inclusion criteria' which facilitated the emergence of broad themes of data.

Frequency of word occurrences were used to establish where common repetition existed. This led to further discussion about emergent themes.

### **2.4 Ethical Approval**

All procedures performed in this study were in accord with the ethical standards of the institutional and national research committees and with the 1964 Helsinki declaration and its later amendments. Permission for the research was granted by the Research Ethics

Committee for Wales (ref:13/WA/0225) and written, informed consent was obtained from all participants.

### 3. Results

#### 3.1 Participants

Table 1 shows the ages of the participants, along with the length of time they had been living with lymphoedema. Participants were all female, with ages ranging from 43 to 86. All had developed lymphoedema in one arm following treatment for breast cancer. The length of time lymphoedema had been present varied from under 1 year to 17 years.

<b>Mean Age in years</b>	<b>Mean</b>	<b>S.D</b>	<b>Min.</b>	<b>Max.</b>
Total (n=26)	60.8	11.8	43	86
Cardiff (n=15)	59.3	9.6	43	73
Tredegar (Hospice) (n=5)	62.4	11.7	51	75
Bridgend (n=6)	63.0	17.7	43	86
<b>Years with lymphoedema</b>	<b>Mean</b>	<b>S.D.</b>	<b>Min.</b>	<b>Max.</b>
Total (n=26)	4.7	4.5	.08	17
Cardiff (n=15)	4.1	3.2	.08	10
Tredegar (Hospice) (n=5)	9.2	6.1	2	17
Bridgend (n=6)	2.4	3.8	.25	10

Table 1. Age and Years with lymphoedema (n=26)

#### 3.2 Interview data

Four themes emerged.

- Physical impacts of lymphoedema on daily life
- Psycho-social impacts of lymphoedema
- Experiences of physical change during and after reflexology treatment
- The return of optimism

Within these themes, a range of personal experiences were identified, linked to body image and self confidence, pain and swelling, wellbeing and re-engagement with activities. These are outlined below, along with illustrative quotations from the participants. Participant's quotations are coded with a letter indicating the centre from which the data was collected, (H for Hospice of the Valleys Tredegar, C for Cardiff, B for Bridgend) and a number for each participant.

<b>Themes</b>	<b>Sub themes</b>
Physical Impacts of Lymphoedema on daily life	Swelling
	Pain
	Sleep

	Impact on daily functioning
	Mobility
Psycho-social impacts of lymphoedema	Social embarrassment
	Clothing
Experiences of physical changes	Visible change
	Reduction of pain
	Fluid movement
	Improvement in other conditions
The return of optimism	Re-engagement with usual activities

Table 2: Themes and Sub-themes

### 3.2.1 Physical Impact of lymphoedema

#### Swelling

Physical changes after the development of lymphoedema were discussed by all participants, with the majority making reference to the swelling of the arm as a main concern.

*“ ..some days it was very painful- the swelling, and also I found that I couldn’t form a fist with my hands, there was so much. Also things began to get tight, like my watches and things like that.” C9*

In some participants, the swelling occurred under the arm or around the back of the shoulder, which could be difficult to conceal, as illustrated below.

*“ Yes my left hand was very , very swollen, even down to my fingers. I wasn’t able to wear my rings or my watch on that hand. And people always noticed ‘ Oh what’s the matter with your hand?’ ...but also the top of my arm, I used to call it my plum because it was quite swollen and it looked discoloured.” H1*

Patterns of discomfort varied across the sample with the retained fluid settling in different parts of the arm in different individuals.

*“...it was really uncomfortable , from the elbow up was very tight and under the arm was really uncomfortable, it was like a football underneath all the time.” C10*

The swelling was also linked to other effects such as impairment of sensation, or temperature.

*“...absolutely no feeling in the back of my arm at all” C5*

*“...I’ve physically then just got to put my other arm on top of it to give it a bit of warmth.” C5*

## **Pain**

The pain which accompanied the swelling was identified as a secondary concern for half of the participants.

*“It was a real nightmare, it was really painful, it was like a blood pressure cuff permanently on my arm, so I had that permanent throbbing.” C15*

Reconstruction surgery was sometimes a factor in the patterns of pain experienced by some of the participants as illustrated below.

*“With having the breast surgery and the reconstruction of my back, the whole quadrant you know aches and pulls all the time, it’s not comfortable. But on top of that, when the lymphoedema increased there was a lot of pain in the upper part of my arm and around my back and into my breast...” C6*

## **Sleep**

Pain, swelling and heaviness in the upper limb and associated areas where surgery had taken place, had a negative impact on sleep for many of the participants.

*“It was very heavy, the swelling was making my arm ache, it was just an overall big ache, it was uncomfortable when I was sleeping” B4*

Some participants suffered from disturbed sleep due to the constant aching, and found it helpful to raise the arm during the night.

*“...the top of my arm used to ache like toothache. I would put pillows by the side of me at night to rest my arm and try and get a bit of comfort. It would keep you awake in the night and it was just uncomfortable...” H1*

## **Impact on daily functioning**

The pain associated with lymphoedema had other consequences by restricting movement and affecting the ability to carry out normal daily activities, such as driving a vehicle, housework or carrying shopping.

*“My arm was actually quite bad on some occasions, some days would be worse than others especially if I did ironing, cleaning windows or even painting, um it would cause me quite a problem. Painful, it was painful..” C14*

Connections were made between usual activities like housework and the onset of pain in the swollen limb.

*“..... a lot of aching, pain really, mainly in the top part, but also a little bit just below the elbow, quite severe, especially if I had done any sort of housework.” H4*

A fear of making things worse had the effect of people withdrawing from their usual activities, as illustrated below.

*‘I had the pain in the back of my arm, which can be unpleasant. I’m not able to carry shopping with my left arm at all, because if I do I pay for it, you know, I get more pain and I have pain if I try to carry with my arm, it’s not as strong as my right arm.’ H6*

Participants recognised what worsened the condition, but refraining from necessary activities proved to be more difficult.

*‘I didn’t have any pains at all when I was resting. If I did absolutely nothing all day I would be fine. Even driving the car I had pains in my arm and around my elbow and under my arm as well.....and of course some days you can’t avoid but do these things.’ C14*

Driving was a common trigger for the worsening of symptoms, and one participant suggested that it was driving which initiated her first experience of lymphoedema.

*“....the minute I drive is the minute my lymphoedema plays up, that’s what brought it on in the beginning you know..” H4*

## **Mobility**

Impaired functioning in arm and shoulder resulted in a limited range of movement, sometimes restricting their usual exercise routine which helped keep the arm mobile.

*“....Very tight, even though I still continue to do exercises I was given when I was in the hospital...., but most days to reach my arm up to get something I used to have pain and it used to pull. So you would only use the arm really if you really had to use it.” H1*

Fear of making their pain and swelling worse removed previous ways of being, replacing them with new patterns of movement and engagement, more suited to someone with limited capacity.

There was also an impact on their working lives, where pain restricted their normal activities in the workplace.

*"I've got swollen fingers, even on my good hand, and I do a lot of writing in my job, so I write, I put the pen down, I rest my arm...."* **H1**

There was evidence of vigilance in self care, and a proactive approach to dealing with any deterioration so they could carry on with their usual lives.

*"I found work was worse because your arm, when you are typing all day as a medical secretary and your arms are in the same position..... so I found every so often I had to start doing my exercises to try and relieve the pain because it was worse in situations like that"* **C15**

### **3.2.2 Psycho-social impact of lymphoedema**

The effects of lymphoedema were not limited to the physical, and there were a range of psychosocial impacts identified in the interviews. One of the main issues to emerge was the effect of the swollen limb on their own body image.

Physical change led to feelings of 'difference' both as compared to those around them and as compared to the person they once were. References to the difference in self confidence were common in the interviews.

#### **Social embarrassment**

The disfigurement caused by a visible difference in their two arms had an effect on their social interactions.

*"I was quite conscious of it if I was talking to somebody or having a picture taken I'd sort of put my arm behind my back. I was really quite embarrassed about it actually, I know it's stupid, but it really was to the extent that I almost felt deformed because my arm was that bad."* **C3**

Being identified as someone who had suffered breast cancer was unpalatable for the participants, and they were keen to avoid being 'categorised' in this way. The things which previously identified them as the person they once had been were swept aside in the wake of serious illness. The swollen arm or the compression sleeve marked them out as different and acted as a visible reminder of their breast cancer.

*".. it's a constant reminder of the fact you've had surgery for breast cancer, you know. Like walking around with a big badge."* **C1**

Some felt the need to lie to deflect questioning

*“...because of my job, wearing a sleeve people think ‘Oh, she’s had a problem’, so some parts of the day I wouldn’t wear it, especially if I was working in the hospice, where people would know, a lot of the patients are in the same boat as myself.....and I didn’t want to talk about myself so I’d say ‘Oh no, I’ve got bad arthritis’ I would lie about what my problem was, you know. You don’t like lying to people, but you just don’t want to have to have... that conversation” H1*

## **Clothing**

Personal identity is reinforced by the outward appearance of the individual, and being unable to wear the clothing they would usually wear was a stressful factor for many of the participants.

*“There was lots of items of clothing that I wasn’t able to wear because when I put them on, you could see my arm was tight there was no movement in the clothing around my arm... which was noticeable to people ..” H1*

*“.. most of my clothes were out of bounds because my arm was too swollen I couldn’t get it in and it’s made a huge difference.” C15*

### **3.2.3 Physical changes**

At the end of the 7 week study, when reflexology lymphatic drainage had been completed, reductions in arm swelling were reported in all participants, and this was the most commented on aspect of being involved in the study. Physical changes in the size of affected arm were noted, along with accompanying reductions in pain.

#### **Visible change**

Sometimes it was a family member who commented on the difference, as indicated here.

*“The swelling has gone down immensely and my husband even commented on it. I think because I have got it every day I don’t notice it as much but I look at myself in the mirror now and I can see there’s an actual shape to my arm whereas before it went straight down. So yeah, it’s good.” C5*

#### **Reduction in pain**

The reduction in swelling was accompanied by improvements in levels of pain and mobility.

*'I have to say..... there's been no pain, there's been no pulling down really from the shoulder into the arm and it feels lighter, the whole arm feels lighter and much more mobile.'* **C6**

*"it has made a big difference, no pain is the main thing, it's fantastic being without that pain."* **C15**

*"Yeah it was quite uncomfortable, it was pulling quite a lot but I find now since I've had the therapies I can move my arm a lot better."* **B4**

*'I have got more movement because the pain isn't there when you move it.'* **H4**

### **Fluid movement**

Prior to the start of the reflexology sessions, there was a good deal of scepticism about the prospect of any improvement.

*'...I really didn't know what to expect because I've never had the effects of reflexology before and I was really quite sceptical thinking 'This isn't going to work, but I'll do it anyway' and I was totally amazed, really, totally amazed to see the difference in my hand after the first session was just, I couldn't get over it'* **C3**

During the reflexology sessions, participants reported a variety of sensations in their affected arm, including tingling, warmth or a trickling sensation.

*'.....a sort of rippling effect in my arm, sort of little ripples down'* **B2**

*'...almost like as if there was warmth in my arm, and I remember one particularly there was something moving in my arm'* **B7**

### **Improvement in other conditions**

There seem to have been peripheral benefits from reflexology treatment, with some participants reporting improved sensation in areas where they had reduced feeling either due to the retained fluid, or as a result of treatment for their cancer.

*'With the peripheral neuropathy I feel that's subtly different and improved, I've got neuropathy in both hands after the chemo, and I think the back of my arm where I had very reduced sensation through the surgery, that actually feels better as well and I feel like I've got more feeling in that area.'* **C1**

A return of sensation was reported by this participant who had also experienced numbness for some time.

*'my feeling's beginning to come back, my nerves are being to come back after 3 years, it was all numb and it's all beginning to come back.'* **C9**

Some of the participants noted that they felt better in other ways after being involved in the reflexology study. Reduction in joint pain for this participant:

*'So it's been not only for the lymphoedema, it's been beneficial for my joints as well. I mean like yesterday I walked, I couldn't do that at one time, I'm sure it's because of that.'* **C9**

Another participant found that retained fluid appeared to be improved in her lower limbs as well as her affected upper limb.

*'Because I do have some fluid around my ankles and both times, we went into [supermarket] and my shoes were flipping off and I said it was the same the week before. So that's good.... it's lovely.'* **C13**

### **3.2.4 The return of optimism**

Many of them had settled in to a pattern of being which accommodated their swollen arm, and had begun to withdraw from the lives they led prior to the breast cancer. The ability to wear what they would have worn prior to the lymphoedema presented an opportunity to return to the life they lived before, as the person they were before.

*"I can fit into blouses that I couldn't fit into before because the swelling isn't so bad. And my jackets, leather jackets, you know, sometimes you feel a little bit restricted around the arm, they now fit comfortably."* **C14**

Finding another way to treat their lymphoedema was considered a positive experience, allowing feelings of optimism to emerge.

*'I've really found it's really helped and I'm really pleased I did it because it's opened another door for me for treatment'* **C13**

### **Re-engagement with usual activities**

Fear of making things worse was common amongst the participants, and they were proactive in managing their own arm swelling by avoiding tasks which might have a negative impact. But this further removed them from the person they were before. Hobbies like gardening were subject to strict self-limitation. After the project, people began to re-engage with their usual activities.

*‘I enjoy gardening and I did a little bit last week which I haven’t done for a long time, so that was good, I enjoyed doing that, the fact that I’d achieved something. I was always afraid to do it before.’ B2*

Some participants felt able to return to their work activities without the usual repercussions.

*‘...I do hairdressing part time, so I only do my regulars because I’ve done it years and I noticed I had quite a busy day yesterday so it ached a little bit last night but nothing that I had to go and take tablets for. When I think I did have quite a busy day I thought it was good, I did a perm so your arms are up quite a lot, and I’m left handed which is my bad one and..... I think I was dreading it but it was good, really good.’ C13*

#### **4. Discussion**

The experiences of the women in this paper indicated that lymphoedema had a variety of effects on their daily lives. Involvement in this feasibility study into reflexology lymphatic drainage was considered a positive experience. The data highlighted the daily impacts of BCRL, and indications are that benefit was perceived on both physical and psychological levels.

Going through the breast cancer experience had clear impacts on identity and being categorised as a cancer sufferer was unwelcome. The constant reminder of disfigurement acted as an inhibitor to engagement with life as the person they were before. Whilst there was a feeling that they had moved on from their original diagnosis, the wearing of a compression garment further identified them with their illness.

Disfigurement and feelings of poor body image were evident in many of the participants’ accounts, which corresponds with other authors’ findings around quality of life in patients with lymphoedema [34].

In this small sample of 26 women, management of lymphoedema involved a complex interaction of preventative care and avoidance of excessive use which could exacerbate the condition. This fear was a common barrier to re-engagement with the life previously lived before breast cancer. Daily activities such as driving and housework could not be carried out as they were before. This had the effect of removing them from their normal societal roles and maintaining their status as a ‘sick’ person.

The reflexology sessions appeared to empower them to reconnect with the person they once were, re-engaging with work life and hobbies. This in turn set them on an upward trajectory

of health and wellbeing, in place of a downward trajectory of illness, disfigurement and disability. This reconnection with 'self' was both comforting and reassuring, leading to a renewed optimism for their future.

Current lymphoedema treatments, such as the wearing of compression garments is beneficial, but further improvements from symptoms may be provided by harnessing complementary interventions such as reflexology. Such non invasive treatments can offer time and space outside a clinical environment and there may be improvements in mood and psychological distress. [5]

Preventative care of their swollen arm, whilst establishing good management of lymphoedema, sometimes inhibited them from reconnecting with activities they once engaged in. Some studies suggest that self care advice may vary and this itself may have a profound effect on the patient's quality of life [35]. Participants in this study were well versed in what not to do, but this caused a fear of recurrence which for some participants became the overriding factor preventing them from re-engaging with life.

This study highlights the daily impact of lymphoedema, and suggests that management of the condition is much more than compliance with treatment options such as compression garments and preventative care. [36]. The data suggests that patients are keen to be a partner in their own recovery and maintenance of health, and that there is an appetite for experimenting with innovative treatments which in addition to being pleasant and non invasive, may deliver other health benefits alongside improvements in pain and swelling.

#### **4.1 Limitations**

The qualitative data presented here were collected at the end of a study which measured physical changes in lymphoedema of the arm after four sessions of reflexology lymphatic drainage. The use of focus groups to collect data about women's experiences of living with lymphoedema might have yielded richer data. However the project was limited by time and location and the qualitative data capture was added to the original goal of the study which was to explore whether a lymph drainage effect was present.

This study examined a small sample of 26 women, and within this group there was no fixed pattern of lymphoedema, and management strategies varied by individual. There is a need for further research into the adherence patterns for wearing compression garments, along with other means of BCRL management, and how these behaviours impact experiences of BCRL.

Lymphoedema of the arm can fluctuate in an individual for a variety of reasons including weight gain or loss, hot weather influencing the patient's comfort in wearing the compression

garment, and over use of the arm. Compression garments may need resizing over time because of these fluctuations, as some are rendered less effective if they are too tight or too loose. During the study, data was only collected on general patterns of wearing of the compression sleeve. Future research might usefully explore how often participants accessed the lymphoedema service, and the frequency of compression sleeve alteration. There is a need to understand what method of compression garment use is most effective, and how much fluctuations in sizing of compression garments influence the progress of lymphoedema.

MLD (Manual lymphatic drainage) is a method of light massage offered to BCRL patients as a management intervention. Availability of this method is thought to vary nationwide and none of the participants were accessing this method during the trial. Further research might usefully be conducted to compare these two interventions for effectiveness and availability to patients with BCRL.

Participants were offered weekly reflexology sessions, which were conducted over four consecutive weeks. There is no data on how often MLD might usefully be applied to BCRL patients, nor how widespread a service is available within the UK.

Whilst the qualitative data adds depth to the quantitative findings by expanding on what was most challenging in daily life, it cannot support the introduction of RLD as a recommended treatment without further exploration of the technique.

Reflexology is a general term for a variety of types of manual intervention using fingers and hands applying pressure to parts of the feet. It is practiced worldwide and there may be a variety of techniques embedded within the term 'reflexology'. In common with other types of therapeutic treatment, reflexology is a complex interplay of personal interaction, relaxation techniques, and the physical application of touch. Coupled with cultural expectations, and the opportunity for conversation and relaxation, it is challenging to control for all variables involved. Future research might use a randomised controlled trial to control for some aspects of therapeutic touch and placebo effects.

Reflexology is one of the most commonly used complementary therapies accessed by cancer patients [18]. However, the evidence base for its effectiveness remains limited, and broader safety implications continue to be largely unexplored resulting in limited availability of treatment within the NHS. RLD is a specialised protocol of targeted reflexology and it is not yet clear whether this differs substantially in effect as compared to other types of reflexology treatment.

Further research might also explore links between quality of life and the reduction of swelling, although the two are not necessarily closely correlated [37]. Whilst the data were able to highlight the concerns of a small number of individuals, further research is indicated to quantify the impact of RLD on quality of life using a lymphoedema specific quality of life scale both as benchmark and as barometer of change [37].

## **5. Conclusions**

The impact of lymphoedema on daily life, psycho-social interactions, physical change and feelings of optimism are highlighted in this study. The self categorisation of 'sick person' or 'well person' had implications for the participants' psychosocial trajectory in a positive or negative direction.

The study illustrated that BCRL patients in this sample are highly motivated in their own care routines, incorporating a range of strategies in the prevention of exacerbation of the condition. However their adherence to treatment plans, in this case the wearing of compression garments was affected by their reluctance to be labelled as a breast cancer patient. Further information on factors influencing adherence would help develop caregiver strategies to encourage better adherence to treatment plans.

Access to therapeutic treatment for BCRL varies widely across the NHS in the UK. It is not clear how the RLD technique compares to manual lymphatic drainage (MLD) and other therapeutic treatments. Further research is indicated into measurement of impact of different treatments on lymphoedema related to breast cancer.

## **Conflict of Interest**

Author C provides training for practitioners in the RLD technique of reflexology.

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