



Thomas, M., Coveney, E., Pike, C., Morgan, K. and Noble-Jones, R. (2020) Exploring the impact of lymphoedema on individuals and if lymphatic venous anastomosis surgery effects perceptions on quality of life: A qualitative study. *European Journal of Oncology Nursing*, 44, 101720. (doi:10.1016/j.ejon.2019.101720)

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/209094/>

Deposited on 10 February 2019

Enlighten – Research publications by members of the University of  
Glasgow

<http://eprints.gla.ac.uk>

## Original Research

### **A qualitative study: Exploring the impact of lymphoedema on individuals and if Lymphatic Venous Anastomosis Surgery effects perceptions on quality of life**

Dr Melanie Thomas, MBE DProf FCSP, National Clinical Lead for Lymphoedema in Wales, Swansea Bay University Health Board

Elizabeth Coveney, RCR (T) MSc, National Lymphoedema Specialist, Swansea Bay University Health Board

Cheryl Pike, MCSP, National Macmillan Lymphoedema Specialist, Swansea Bay University Health Board

Karen Morgan, NMP, PGCE, BSc (Hons), RGN, National Lymphoedema Education and Research Lead, Swansea Bay University Health Board

Dr Rhian Noble-Jones, PhD MCSP, National Lymphoedema Research Specialist, Swansea Bay University Health Board

Correspondence; Melanie Thomas, Lymphoedema Network Wales, Swansea Bay University Health Board Cimla Health and Social Centre, Neath, Wales. SA11 3SU

[Melanie.j.thomas@wales.nhs.uk](mailto:Melanie.j.thomas@wales.nhs.uk)

**Declarations of interest:** none

**Key Words-** Adjustments, Cancer Consequences, Hope, Lymphatic Venous Anastomosis, Lymphoedema, Quality of Life, Survivorship

**Funding Source:** Tenovus Cancer Care provided a research grant to fund this study.

## **Abstract**

### **Purpose**

Lymphoedema is a chronic condition, a cancer consequence and causes physical, psychological, and social implications. A new super-micro surgical treatment Lymphatic Venous Anastomosis (LVA) may improve the symptoms of lymphoedema. This study aims to explore the impact of lymphoedema on individuals and if LVA Surgery changes perceptions on quality of life.

### **Method**

Semi-structured interviews were conducted with sixteen individual's pre-LVA surgery and repeated six months later post-LVA with ten of the participants. Transcripts were analysed using thematic analysis.

### **Results**

Themes identified pre-LVA included: Impact of Living with Lymphoedema, Being Different, and Future Hopes and Emotions. Participants reported making significant changes to 'normal' life due to living with lymphoedema. Changes included alteration in shopping, cleaning, hobbies, familial roles, employment and sexual intimacy. The wearing of compression garments engendered feelings of being unattractive. Themes found post-LVA were: I am one of the Lucky Ones and Returning to Former Self. Post-LVA, participants described how life had become more normalised with fear and apprehension of developing cellulitis reduced. Positive changes had enabled usual activities of daily living to recommence. Some participants had decreased pain, aching, heaviness, stiffness and were wearing their compression garments less.

### **Conclusion**

The findings suggest that the real impact of living with lymphoedema is much more challenging than previously identified. The findings suggest that LVA can give a future of greater choice for some of its recipients, but further research should explore longer-term benefits. LVA could offer hope to some people with lymphoedema, but a realistic expectation is essential.

## Introduction

The numbers of people surviving cancer continue to increase due to earlier identification and better treatments. However, many people subsequently face long-term consequences of the disease and its treatments, which include lymphoedema (Krok-Schoenet et al. 2015). Lymphoedema is a chronic condition, which is caused by a failure of the lymphatic system occurring through disruption to the transport capacity (lymph node removal) or overloading in the tissues (Browse et al. 2003). As well as cancer, secondary lymphoedema can also occur from trauma, vascular or dermatological disorders, obesity, or can be a primary condition occurring as a result of lymphatic malformation. Lymphoedema has been branded an incurable problem characterised by distinct swelling of the tissues (Moffatt & Pinnington, 2012). Skin changes can also occur, leading to hyperkeratosis, papillomatosis, and recurrent cellulitis (Mortimer, 2018). Swelling can affect any part of the body but is common in the upper or lower limbs.

Studies have shown that in many cases lymphoedema will affect Quality of Life (QoL) as it can lead to pain, skin tightness, heaviness, numbness and reduced range of movement (Greene & Meskell, 2017; O'Toole et al. 2013). Reports also indicate that lymphoedema affects psychological and emotional wellbeing instigating altered body image, anxiety and depression (Shaitelman et al. 2015; Chachaj et al. 2010; Armer et al. 2004; Herberger et al. 2017). Furthermore, a previous study of the impact of lymphoedema on employment highlighted that 80% of patients were off work, 9% changed their employment status, 2% switched jobs, and 8% gave up work entirely (Moffatt et al. 2003).

Historically, conservative lymphoedema care has been dependent on maintaining and averting exacerbations as well as preventing the development of cellulitis, which can affect around thirty percent of patients (Mihara et al. 2014). Conservative lymphoedema management consists of four cornerstones of care, namely skin care, exercise/movement, compression, and lymph drainage (Thomas et al, 2017). Health care professionals advise people with lymphoedema to commit to a daily self-care programme to manage their lymphoedema. However, the mainstay of treatment is wearing compression garments throughout each day for the remainder of a patient's life (ILF, 2012). Compression garments can cause implications for hobbies, familial roles, employment as well as intimacy due to the visual appearance and fabric restriction. Furthermore, as many patients develop lymphoedema because of cancer, it is reported as being a constant reminder of their malignancy journey (Morgan et al. 2005).

For those patients with complex or severe lymphoedema, intensive treatment is offered requiring the patient to attend a lymphoedema clinic daily for a course of Manual Lymphatic Drainage (MLD) massage and multi-layer lymphoedema bandaging. These bandages need to remain in situ for the duration of treatment, which can take 2-4 weeks and can cause difficulty in normal functional activities. All in all, living with lymphoedema can be physically, psychologically, emotionally, and socially demanding (Moffatt et al. 2017).

Surgery for lymphoedema has advanced in the last few decades from widespread tissue removal, such as the Charles procedure, to physiological techniques, e.g. lymph node transfers, and minimally invasive techniques such as lymphatic venous anastomosis (LVA). LVA attaches inadequate lymph vessels to veins (Ramsden et al. 2015; Leung et al. 2015). Research has suggested that LVA can provide a 96% chance of symptom relief and a 74% chance of reducing the need to wear compression garments (Chang et al. 2013). Cellulitis episodes have also been shown to decrease after LVA surgery (Mihara et al. 2014). The benefits of LVA may take up to sixteen months to establish, allowing for consolidation of the new lymph-venous bypass (Masia et al. 2016).

Undergoing LVA surgery is presumed to have a positive impact on the lives of those living with lymphoedema. However, given that very little is known about the perceived effect on the QoL of people undergoing LVA, a qualitative methodology was chosen to explore this subject further. Therefore, the overarching aim of this study was to explore, the impact of LVA on the perceived quality of life of people with lymphoedema to inform future clinical practice. Meeting the aim of this study, the objectives were to:

1. Explore the existing impact of lymphoedema on QoL of individuals before undergoing LVA,
2. Discover if having LVA surgery changes patient's perceptions of their QoL.

This research could provide valuable information to support further developments and accessibility of LVA surgery. Moreover, this research could help inform future patients considering this procedure and assist them in making a more informed choice.

## **Methods**

### Participants and recruitment

The study involved adults aged 18 or over, living in Wales, United Kingdom, who had been diagnosed with lymphoedema from cancer or non-cancer origin and were able to provide informed consent. All participants were eligible for LVA surgery after clinical assessment. Interviews were chosen as the methodology choice to understand each patients' individual beliefs and experiences of lymphoedema.

An independent Lymphoedema Specialist (CP) informed all eligible participants of the research study. Potential participants were issued with a patient information leaflet and invitation letter, then contacted by telephone to provide additional information and answer any questions. An interview was planned before the LVA surgery and for six months afterwards. Each participant completed a consent and demographic form before the start of the study. The study aimed to recruit until saturation was reached and/or within the study time limits; initially targeting approximately (15) participants as per similar qualitative studies (Meraviglia & Stuifbergen, 2011). Camden & Kings Cross Ethics Committee (15/LO/12775) granted ethics approval.

### **Data collection**

Demographic data, which included gender, age, lymphoedema site, and history, were collected. All the semi-structured interviews were carried out by a Lymphoedema Specialist (EC); pre-LVA surgery in September-December 2015 and post-LVA interviews in March-June 2016. Initial interviews lasted approximately 60 minutes, post-LVA interviews lasted an average 45 minutes. Each interview was recorded and transcribed verbatim. Topic guides (Table 1), developed by MT, EC, and KM, consisted of a series of open questions on the impact of lymphoedema pre-and post LVA surgery respectively. During the interviews, the researcher (EC) had minimal verbal input and prompted only when appropriate (Oppenheim, 1992).

### **Analysis**

Thematic Analysis (Braun & Clarke, 2013) was used to provide a detailed description of the data and to ascertain themes using a realist approach. Initially, two researchers (MT and EC) independently undertook detailed analysis commencing with classification into codes, categories and then themes and comparing amongst the different participants until achieving saturation. Later, the two researchers collaborated, amended and refined until reaching agreement on all the topics. This method facilitated crosschecking of similarities and differences within the data. The aim in this process was an explicit engagement with the data

rather than objectivity, therein acknowledging that the researchers' perspective is based on their experience (Gadamer 2013). This is of particular relevance in studies conducted by clinician-researchers.

## **Findings**

### **Participants**

Sixteen participants were interviewed pre-LVA surgery, while the post-LVA interviews had ten participants due to study time and funding constraints (Table 2). Fourteen female participants undertook pre-LVA interviews reducing to nine post-LVA, and of two males interviewed pre-LVA only one participated in the post-LVA interview. A large proportion of lymphoedema patients are women treated for breast cancer; therefore, the gender ratio is as expected.

The average age of the participants was 53.75 pre-LVA *cf.* 51.4 post-LVA, ranging from 24-76 pre-LVA *cf.* 24-67 post LVA. All participants were white and of a Welsh origin. Five had lower limb lymphoedema (three post-LVA), and eleven had upper limb swelling (seven post-LVA). Fourteen of the initial participants had lymphoedema from a cancer origin (nine in post-LVA group), and two were non-cancer related (one post-LVA). Breast cancer was the most common diagnosis amongst the cancer participants (89% of pre-LVA participants *cf.* 79% post-LVA).

### **Pre-LVA Interview Themes**

Three main themes were identified in the pre-LVA interview data: the impact of living with lymphoedema, being different, and future hopes and emotions. As can be seen in Table 3 each theme had subthemes supported by verbatim participant quotes.

#### **The Impact of Living with lymphoedema**

This theme had many subthemes including impact on employment, lifestyle practicalities, desires for the future and fear.

The participants highlighted the significant adjustments made to their employment due to having lymphoedema. Modifications were required even if their job was described as physical or sedentary.

*"I have given a lot of them up; [cleaning jobs] I've had no choice" (12).*

*"I was a manager and had quite a lot of sitting in meetings, and I used to get... discomfort in the leg and I'd have to keep moving the leg around beneath the table. On occasions, I'd have to get up and go for a walk." (09).*

Furthermore, having lymphoedema also affected participants financially as they had to alter their previous working role. This raised anger and frustrations with participants in how lymphoedema had altered their lives.

*"I ended up having to go onto redeployment due to the compression garments [being an infection risk]; ...which...affected my pension and everything else." (01).*

Participants also described modifications to home life including housework and shopping due to lymphoedema as they encountered reduced movement and muscle strength in their limbs.

*"Doing chores, changing beds and things like that it takes me longer." (05).*

*"It's like going to the supermarket, I'll take a trolley rather than a basket to carry food in, and I use more carrier bags than I did before because I'm lifting less weight when I'm putting the shopping back in the car." (08).*

Living with lymphoedema also evoked changes in pre-existing familial roles with participant (04) describing discomfort at having to ask her husband to do cleaning chores, which he disliked causing her to feel inadequate.

Even leisure activities including cycling and going to the gym had changed in response to living with lymphoedema causing sadness, as participant (03) described:

*"My husband and I used to go biking. We don't do that anymore because I find it's too painful...I just can't do it."*

Participants also described changes to hobbies such as playing the piano, cooking and pottery:

*"an hour's playing [piano] would mean I am then trying to get the swelling down..., so I don't do that now, and that's a huge disappointment for me." (03).*

Furthermore, participants reported lifestyle alterations due to apprehension surrounding cellulitis and making their lymphoedema worse. One stated how she was so worried about cellulitis that it affected her interests such as gardening and golf.

*"To be so wary [of cellulitis] because I play golf and I like gardening, and when I go out there I'm covered from head to toe. I don't want to get any bites or stings or scratches...I think an infection is one of the biggest worries, isn't it?" (05)*



Lymphoedema and the risk of cellulitis were also described as being factors to altered long-term ambitions and desires such as moving abroad and even worrying about starting a family. This was particularly noted from participants aged 40 and under, where concerns ranged from fears of lymphoedema worsening from pregnancy to disease recurrence.

*"I haven't had children yet ...I think I was almost too scared to find out...I'm too terrified of the answer."* (06).

Fear regarding progression of lymphoedema due to being older and not physically managing or having a cancer recurrence, which would significantly affect appearance, were also expressed by many participants.

*"In the long term, when I'm old, and I can't really be as active...what's going to happen, you know...is it going to get worse?"* (16).

*"From an age point of view ...oh my god what are my legs going to be like when I'm, sixty, seventy?"* (07).

Participants also described the daily practicalities of dealing with lymphoedema, e.g. compression garments needing washing every day; and problems caused by limited prescribing. The types of problems described included having to wash garments in public toilets, wearing the garments when they were dirty and having to alter the choice of clothes they intended to wear to hide the garment. Many participants spoke of the necessity for prior planning, reducing the ability to be spontaneous as lymphoedema was always in the forefront of everything they did.

*"So basically it's clean your teeth, wash your sleeve."* [However], *"when you're traveling ...it is fine if you're in a five star [hotel] but if you're camping!"* (02).

In contrast, one participant said she had not made any adjustments because of lymphoedema,

*"Never have I said, I can't do that because of my lymphoedema."* (14).

### **Being Different**

Two sub themes were identified within Being Different- choices and limitations and physically altered as highlighted in Table 3. Within this study, participants shared stories of being different, not the same as before and longing to be 'normal' again. This was in relation to having to constantly wear compression garments or being unable to wear their clothes/shoes of their choice and in relation to intimate relationships. Many of the participants had

recovered from a diagnosis of cancer and were attempting to return to their normal life; however, lymphoedema made them constantly feel different.

*"I felt normal, and then obviously I had lymphoedema and wearing the sleeve is a physical thing that you can't disguise ... makes it very difficult for me... I don't like it. It's a constant reminder that I was unwell [had cancer]." (08).*

For those who have to wear arm compression garments, they describe being different from others and detesting standing out, *"I just don't like standing out" (01)*, and *"I hate pity, I know it sounds silly, but the last thing I want is for people saying, "oh poor you." (02)*. Furthermore, participant (15) stated that the garment caused pain. *"And it is so uncomfortable...I can't wait to get it off... it is such release as it's such a discomfort."*

Participants reported that lymphoedema prevented normality in terms of choosing clothes and shoes; a view expressed by both male and female participants.

*"I don't wear shorts if I'm wearing the [compression] stocking, or if I go biking I always wear long biking things."(09).*

*"Sometimes when we go out in the summer I can't stay out for that long because it's too hot and stuff like that, and everybody else is wearing shorts and all, there's me in jeans."(16).*

Social events also highlighted the longing to be able to wear whatever clothes participants chose.

*"I'm in t-shirts or sleeveless tops it's all I can wear. I cannot wear jumpers, jackets; you know everything I wear is tight on the arm. Every time in wedding photos, you can see the difference. Just looks distorted" (10).*

Those participants not in a long-term relationship described the need to appear normal when going on a date or meeting someone romantically.

*"it's that whole thing when you undress in front of somebody you've got the [compression] tights on...they see that straight away...I think it's really unattractive so I've got to hide it." (06).*

For participant (01) the story of her cancer diagnosis and lymphoedema were inextricably linked. *"I tend to steer away from relationships in general...I would have to explain why my arm was swollen...explain that I'd had breast cancer. ...So I choose to stay single... So it has affected me."*

For those in long-term relationships, necessary adjustments reminded them they were different: *"It's made different positions in sex a bit awkward...that is the main thing. And we have to be careful, like, he's got to be careful not to rest any weight on me." (11).*

### **Future Hopes and Emotions**

Participants described their initial feelings of worry, excitement, and optimism about finding out about LVA and their hopes of an improvement.

Participant (13) was excited at the prospect of LVA *“Excited...it’s almost like a little glimmer of hope really.”* Whereas (05) was emotionally overwhelmed *“I got a letter to say that I had been accepted, and well I burst into tears on that day because I was just so overwhelmed by it really.”*

However, the hope for change was tainted by the reality that LVA may not work and lymphoedema could forever remain the same

*“You always get in your head that nothing’s going to change...There is no cure, and that’s always in the first sentence isn’t it of any leaflet that you pick up about lymphoedema is that we can’t cure this, you manage it!”* (06).

For many participants it was the glimmer of hope that they would not require the need to wear compression garments.

*“There could possibly be a cure, and for me could possibly mean that I wouldn’t have to wear the compression garments every day.”* (03).

### **The Findings from the Post- LVA Interviews**

At least six months after the LVA surgery, ten of the participants were re-interviewed to understand any potential perceived changes that had occurred in their lives. Two themes were identified which contrasted the previous themes: I am one of the lucky ones and returning to a former self.

#### **I am one of the lucky ones**

Many of the participants felt extremely lucky that they were eligible for LVA surgery.

*“I feel very lucky to have had it.”* (08),

*“I just feel really lucky be able to have it to be honest...I feel a lot more hopeful.”* (01).

Several participants expressed relief, as they had been nervous and anxious in the lead up to surgery due to fear of the unknown. The relief was in part that the operation was not as bad as they had anticipated but also due to the excellent support provided by staff.

*“It wasn’t as bad as I was expecting...I was a bit nervous... but so lucky.”* (05).

*“I think you’re nervous because you don’t know what to expect, but the staff were brilliant...absolutely fantastic... I am so fortunate.”* (06).

### Returning to a former self

Aspects of returning to former self included three subthemes, which were physical changes, financial changes and emotional changes.

For many of the participants physical changes had occurred concerning their lymphoedema. This included an alteration in limb size:

*“Well in the first three months I noticed that my arm was less swollen, my arm was aching less it felt less heavy ...there had been quite a good reduction...I had gone down from a size two to the size one sleeve.” (04).*

Other changes reported included, *“my arm is not so heavy.” (03); “My arm is far more comfortable and feels normal.” (05); “the log-like feeling of my arm...has diminished tremendously...the forearm is almost back to what it was before the Lymphoedema started... I haven’t got a sleeve on at the moment. I’m trying to leave it off 50% of the time.” (02).*

However, two of the participants reported no changes with their limb size *“I don’t feel it has...it was the same.” (06).* One woman voiced her disappointment at the lack of change. *“It’s exactly the same; there’s been no change whatsoever. I can’t get into my jumpers, and everything’s still so tight...I feel as though I haven’t had the operation...disappointment.” (10).*

Positive functional alterations described included, *“I feel it’s definitely improving...I can certainly do things for longer” (02).* For some, the changes were subtle, *“I don’t feel like my hand swells as much...It is actually a lot softer than it ever was before” (01).* For others, their partners noticed the changes in size *“Actually my wife says it’s looking better. She says it’s looking thinner and more like the other one”. (09).* Some participants reported more all-encompassing changes, *“day to day everything has got a lot easier...I can feel the differences...my arm doesn’t hurt ...doesn’t feel heavy...and feels softer; it feels more like a normal arm.” (08).*

A significant change for some participants was having the ability to choose not to wear a compression garment:

*“I went to the Breast Cancer Care fashion show last month, and I didn’t wear my sleeve...I was aware that it felt different, lighter” (05).*

The impact of wearing compression garments had been significant in the pre-LVA interviews. In contrast, post-LVA participants described the joy attached to not wearing garments for as long.

*“Over Christmas, I did leave the sleeve off several days actually, which is a bit of a change for me.” (03)*

*“I take it off in the evening ... and I don’t put it back on whereas before I kept it on.” (05)*

The impact of not having to wear a compression garment also influenced the choices and options of clothes that were worn. This change had both emotional and financial implications:

*“Already I’m wearing things like...tight t-shirt sleeves I have changed to wearing normal clothes...I have got a lovely bracelet on which I haven’t worn for years...it’s nice to be able to have more choice’.(02).*

*“I probably have not bought much because I can get into things that I couldn’t get into’.(03)*

Participants also felt they had greater choice in how to live each day. Participant (02) felt that she had opportunities to *“cook, garden, write, I can write for longer...it’s made quite a difference.”* Later in the interview, she also explained that for the first time she would consider a holiday abroad. *“You know if someone said do you want to go on holiday to South Spain or something like that I would probably say yes, which I wouldn’t have done in the past.” (02).*

Within the interview data, there were examples of how participant’s feelings had altered after undergoing the LVA surgery. Many reported that their fear of having another cellulitis episode had diminished.

*“I used to be quite nervous when I cut myself ... a couple of times in the past, I had cellulitis as a result...when I was recently in Portugal I cut my leg on a rock, and I was more confident about leaving it...before the operation, I would have taken the antibiotics just in case, but I didn’t take them, which shows that I’ve got a little more confidence.” (09).*

Some people reported that returning to their usual self, meant acting normally and doing normal things. *“I’ve also been doing normal things. I haven’t been protecting my arm...like before you know lifting and that sort of thing...and it feels wonderful just not to be wary all the time.” (05).*

Likewise, (01) reports, *“It’s a little bit more normalised. I’m kind of getting on with life a little bit more now and not so stressed about my arm. I think I’m not so afraid of causing a problem...[I’ve] gone back to working four days rather than three...I’ve actually started ironing again, which is something that I had stopped doing.”*

## **Discussion**

The initial findings indicated that lymphoedema caused participants to have a lower QoL, which affected their physical, psychological, and social well-being. Novel to this study was the finding that participants reported feeling fear in doing certain activities, apprehension over developing cellulitis and concern over their long-term futures all due to having lymphoedema. Furthermore, the practical impact of wearing compression garments is significant. Garments cause a burden on their chosen activities of life including meeting and being intimate with partners as well as choosing clothes and shoes. Garment usage also decreased spontaneity in life due to long-term practicalities in obtaining clean stockings.

Overall, the results of the post-LVA interviews indicated that for some, but not all participants, undergoing LVA surgery positively improved their perceived QoL. Within our study, participants discussed how LVA had prompted changes enabling usual activities of daily living, including cooking, ironing, gardening, and cleaning to resume. So too were options of being able to lift, carry and not feeling so worried or stressed about their lymphoedema limbs.

### **Impact of Living with Lymphoedema**

Participants reported making changes to 'normal' life due to living with lymphoedema. The impact, modifications, and practicalities of living with lymphoedema reflect those discussed previously (Moffatt et al. 2003; Frid et al. 2006; Ridner et al. 2012; Williams et al. 2004; de Godoy et al. 2002). As the criteria for LVA surgery was mild to moderate lymphoedema, none of the participants had substantial swelling, described as greater than 20% volume difference between limbs. Despite this, participants reported making significant modifications that decreased their QoL. Neuner et al. (2014) looked at the older breast cancer population and found that people who developed lymphoedema had a greater reduction in QoL. Moreover, the impact of lymphoedema was said to be comparable to being ten years older and was an impact similar to another comorbidity.

Reflecting previous studies, our participants described how their lymphoedema had prompted changes to their activities of daily living, including vacuuming, shopping, ironing, and cleaning (Shaitelman et al. 2015; Fu & Rosedale, 2009). Furthermore, participants had to rely on spouses or family members to support their role at home, causing increased angst. The dependence on others due to their lymphoedema created modifications in family life and hobbies (e.g., cycling, playing the piano) and their familial role (e.g., playing with

grandchildren). Consistent with Burckhardt et al. (2014), participants found that every day was overshadowed by having lymphoedema, affecting personal dependency on others and creating enforced changes to plans for the future e.g. moving abroad and job choices.

In this study, participants reported changes to intimacy due to having lymphoedema in existing relationships and when romantically meeting someone new. The wearing of compression garments was reported as being off-putting and engendered feelings of being unattractive. Consistent with Male et al. (2016), lymphoedema patients were far more vulnerable and had altered sexual identity. Pujols et al. (2010) suggests that feelings of attractiveness and how people they view their bodies is coupled to sexual satisfaction; thus if participants report being self-conscious over their swelling, then this may affect their ability to be intimate. We interviewed participants in and out of relationships and found that those who were in long term relationships suffered fewer emotional consequences. Adjustments were needed but not to the extent of those trying to meet new partners. These findings may help healthcare professionals to understand the vulnerability that lymphoedema can cause people who are single regarding meeting potential partners.

In line with other studies, many of our participants reported disruption to employment from lymphoedema, which affected finances. Consistent with Boyages et al. (2016), breast cancer survivors found that lymphoedema greatly affected the ability to remain employed and comparable to Bulley et al. (2013); we found that people reported stopping or reducing the number of hours worked due to lymphoedema. In a study by Goss et al. (2014), lymphoedema due to manual handling was one of the main reasons why health care professionals had to adjust their routine work after breast cancer diagnosis and treatment. However, within our study, we found one of the main reasons for changes to employment was the necessity for wearing the compression garments, which provoked infection control concerns. Furthermore, some of our participants experienced pity and that having lymphoedema attracted unwanted attention. Further research is needed on the subject of employment and lymphoedema and how it affects normality.

Consistent with Mcwayne and Heiney's (2005) paper on the psychological and social implications of secondary lymphoedema, we also found that restrictions of choice of clothing was found to be an issue for many of our participants. Both the male and female participants expressed their dismay at not being able to wear 'normal' clothes due to their lymphoedema. Participants chose to hide their swollen limb or the compression garments by wearing jeans and trousers instead of shorts in hot weather. Reports of participants always wearing

cardigans or long sleeve tops to disguise lymphoedema were captured. For most participants choosing what to wear related to wanting to hide the garment from others and not wanting to attract attention, pity, or being portrayed as different.

Many of the younger participants wondered how they would manage their lymphoedema when they were older and discussed uncertainty and worry about the future. Self-management such as looking after the skin, donning, and doffing garments was difficult for some of the participants now, and they expressed worry about what the future would bring. Furthermore, a few participants were apprehensive about the exacerbation of lymphoedema due to cellulitis, and if they chose to start a family. These findings have not been readily discussed in the literature and generate a new understanding of the impact of lymphoedema on QoL. However, further research is required, especially as more younger patients, are now being diagnosed with lymphoedema.

Existing literature describes the burden of lymphoedema decreasing the QoL for its sufferers. Compression garments are said to be visually unattractive and a reminder of their cancer experience, requiring reconstruction of normality. However, what is original about this study is the detail of how participants described the practical difficulties of living with lymphoedema. As health care professionals, we provide patients with two lymphoedema compression garments. One of these garments is to wear while the other is in the wash, in line with the daily wash recommendation for peak performance from manufacturers. However, the practical implication of our research suggests that participants have reduced QoL due to the burden of keeping garments clean when living busy lives. A situation which is intensified when on holiday or working away from home, where access to laundry facilities are limited, causing stress and angst. More research is needed to establish the impact of compression garments on the day-to-day life and how professionals can create a more efficient process.

Highlighting and beginning to understand the psychological, physical, and social implications of lymphoedema on life contributes to the knowledge base. It is essential to comprehend how lymphoedema affects people regardless of whether the swelling is mild or severe, and for health care professionals offer care based on the best available evidence (Bradley et al. 2014). All of our participants expressed hope that the LVA surgery would enable them to find normality again with a possible cure. Many equated an improvement in QoL with a reduced reliance on compression garments. Although evidence suggests that LVA will support a reduction of limb volume and cellulitis episodes, health care professionals must



manage this hope and expectation to prevent distress if the benefits of LVA do not transpire and garment usage is still necessary.

### **The Impact of LVA**

Our participants discussed how fortunate they felt by being one of the eligible patients having this new innovative surgery. In Wales, 42 patients per annum are allowed the operation on the NHS (ITV Wales, 2017). In other countries in the UK, a privately funded route is the only option. The feeling of being lucky can be explained by the anticipation that LVA could potentially 'cure' a chronic problem but as with all new surgery, it comes with high expectation and 'hype' which needs management.

Since LVA, our participants reported feeling that life had become more normal and that undergoing surgery had given them the confidence and were less fearful about the future. Participants reported that since having LVA surgery, some had decreased pain, aching, heaviness, and stiffness typical of lymphoedema (Fu et al. 2015; Leyson et al. 2017; Moffatt et al. 2003; O'Toole et al. 2015). These are important positive changes as some of the participants have lived with the physical consequences of lymphoedema for many years and may offer hope for people contemplating having LVA surgery.

Post-LVA surgery some of the participants had noticed subtle changes in being able to lift and carry more, which supported their work. Significantly for one participant, she described how having LVA had enabled her to increase her employed hours, reducing the financial burden of lymphoedema on her life. Furthermore, as one of the main reasons for changes in employment status identified pre-LVA was the necessity to wear a compression garment, the potential reduction in need for garment-wear could have a direct impact on QoL. Many of our participants reported a decrease in the swollen limb size, which supported them wearing their compression garments for less time or not at all. Although lymphoedema is ultimately a chronic condition for most, an encouraging impact of LVA surgery on QoL would be reducing the need to wear a compression garment. Ideally, any reduction in wearing a compression garments for twelve hours a day is encouraging.

An important benefit of LVA that was described by our participants was that due to a decrease in limb size, choices surrounding clothes and jewellery had been resumed. Even normal activities in life, such as going on holidays were also reported to be within reach for

the future since having LVA. A return of choice has enabled some participants to feel normal again and would certainly affect perceived QoL (Trusson et al. 2016).

Within this study, we also found that fear and apprehension of developing cellulitis had reduced since having LVA. Participants reported not taking antibiotics 'just in case' as they would have previously and not worrying so much about cuts and scratches with animals. No participants reported having an episode of cellulitis post-LVA, which has important implications in encouraging normalcy and QoL as well as being financially important for the NHS.

It is essential to acknowledge however that not all participants reported having a positive perceived change to QoL since having LVA, and the disappointment was palpable. Hamilton and Thomas (2015) found that cancer survivors' renegotiated hope after being diagnosed with lymphoedema, and the object of desire was a return to normal. However, due to the hype of LVA being a 'cure' for lymphoedema, some participants had unrealistic expectations of returning to normal. The reality that LVA may not improve symptoms and not cure lymphoedema can be very distressing. Like Barlow et al. (2014), we found that health care professionals had not addressed some of the participant's emotional and psychosocial concerns. This information is essential for healthcare professionals to appreciate before discussing LVA and referring patients as not everyone achieves the outcome they so desperately want.

There are limitations to this study. Due to time constraints, participants were interviewed six months after their LVA surgery. Ideally, the second interviews should have been one-year post-LVA as six months was not long enough to confirm longer-term changes. Moreover, the period of funding prevented all of the sixteen participants to be interviewed post-LVA as many were only a few months post-LVA. In the ten post-LVA interviews completed, only one was a male participant. The sample was therefore predominantly female and was not culturally diverse and the majority of the respondents were affected by lymphoedema from cancer however, there is still value in the findings identified.

The qualitative findings found in this study have not been discussed in the literature previously in relation to the context of LVA availability. It generates new understanding, but further research is needed on the in-depth experiences of people undergoing LVA surgery and the changes to QoL. The positive implications of experiencing LVA reported by our participants are noteworthy and supports the ongoing availability of this type of surgery.

## Conclusion

In conclusion, our findings suggest that the real impact of living with lymphoedema is much more challenging than previously identified, especially the influence of compression garments on daily life. The longing to return to a normal devoid of lymphoedema was evident. Our findings suggest that LVA surgery offers the potential for positive change to QoL for people diagnosed with lymphoedema. This small study found that many patients receiving LVA for lymphoedema described positive change to the physical, psychological, and emotional impact on QoL. As health care professionals, we have a duty of care to provide information on LVA that supports the hope experienced but does not offer unrealistic expectations. The findings suggest that LVA can give a future of greater choice for some of its recipients, but further research should seek to explore any longer-term benefits.

## References

- Armer, J., Fu, M. R., Wainstock, J. M., Zagar, E. & Jacobs, L. K. (2004). Lymphedema following breast cancer treatment, including sentinel lymph node biopsy. *Lymphology*, 37:73-91.
- Barlow, S., Dixey, R., Todd, J., Taylow, V., Carney, S. & Newell, R. (2014). 'Abandoned by Medicine'? A qualitative study of women's experiences with lymphoedema secondary to cancer, and the implications for care. *Primary Health Care Research & Development*.15:452-463. Doi: 10.1017/ S1463423613000406
- Boyages, J., Kalfa, S., Xu, Y., Koelmeyer, L., Mackie, H., Viveros, H., Taska, L. & Gollan, P. (2016). Worse and worse off: the impact of lymphoedema on work and carer after breast cancer. *Springer Plus*. 5:657.
- Bradley, P., Willson, A., Buss, P., Harry, S., Laing, H., Shortland, G. & Woerden, H.V. (2014). Achieving Prudent Healthcare in NHS. Retrieved on July 29, 2019, from Wales. <http://tinyurl.com/l4oflh4>.
- Braun, V. & Clarke, V. (2013). Successful Qualitative Research a practical guide for beginners. London, Sage.

Browse, N., Burnand, K.G. & Mortimer, P.S. (2003). *Diseases of the Lymphatics*, London, Arnold.

Bulley, C., Coutts, F., Blyth, C., Jack, W., Chetty, U., Barber, M. & Tan, C.W. (2013). Prevalence and impacts of upper limb morbidity after treatment for breast cancer: a cross sectional study of lymphoedema and function. *Cancer Oncol Res.*1 (2):30-39.

Burckhardt, M., Belzner, M., Berg, A. & Fleischer, S. (2014). Living with breast cancer-related lymphoedema: A synthesis of qualitative research. *Oncol Nursing Forum.* 41:4. E220-E237.

Chachaj, A., Malyszczak, K., Pyszczel, K., Lukas, J., Tarkowski, R., Pudelko, M., Andrzejak, R. & Szuba, A. (2010). Physical and psychological impairments of women with upper limb lymphedema following breast cancer treatment. *Psychooncology*, 19:299-305.

Chang, D.W., Suami, H. & Skoracki, R. (2013). A prospective analysis of 100 consecutive lymphovenous bypass cases for treatment of extremity lymphoedema. *Annals of Vascular Surgery.* 132:1305-1314.

De Godoy, J.M.P., Braile, D.M., de Fatima Godoy, M. & Longo, O. Jr., (2002). Quality of life and peripheral lymphoedema. *Lymphology.* 35(2):72-75.

Frid, M., Strang, P., Friedrichsen, M.J. & Johansson, K. (2006). Lower limb lymphedema: experiences and perceptions of cancer patients in the late palliative stage. *Journal of Palliative Care*, 22:5-11.

Fu, M. & Rosedale, M. (2009) Breast cancer survivors experiences of lymphoedema related symptoms. *J Pain Symptom Manage.*6:849Y859.

Fu, M.R., Axelrod, D., Cleland, C.M., Qui, Z., Guth, A.A., Kleinman, R., ... & Haber, (2015). Symptom report in detecting breast cancer-related lymphedema. *Breast Cancer (Dove Med Press)*, 7, 345–352.doi: 10.2147/BCTT.S87854.

Gadamer, H.-G. (2013). *Truth and Method (Bloomsbury Revelations)*. London: Bloomsbury Academic

Goss, C., Leverment, I.M.G. & de Bono, A.M. (2014). Breast cancer and work outcomes in health care workers. *Occupational Medicine.* 64:645-637. doi:10.1093/occmed/kq122.

Greene, A. & Meskill, P. The impact of lower limb chronic oedema on patients' quality of life. *International wound journal.* 2017; 143:561-8.

Hamilton, R. & Thomas, R. (2015). Renegotiating hope while living with lymphoedema after cancer: a qualitative study. *Eur Journal of Cancer Care*, 3: Doi:10.1111/ecc12382.

Herberger, K., Blome, C., Heyer, K., Ellis, F., Munter, K-C. & Augustin, M. (2017). Quality of life in patients with primary and secondary lymphoedema in the community. *Wound repair and Regeneration*, 00-00-00. doi:10.1111/wrr.12529.

International Lymphoedema Framework, (ILF), (2012). Best Practice for the Management of Lymphoedema. Compression Therapy: A position document on compression bandaging.

ITV Wales, (2017). Retrieved on August 5, 2019, from <https://www.itv.com/news/wales/2017-02-13/welsh-hospital-is-the-only-one-in-the-uk-to-perform-a-type-of-super-microsurgery/>

Krok-Schoen, J. L., Oliveri, J. M., Kurta, M. L. & Paskett, E. D. (2015). Breast cancer-related lymphedema: Risk factors, prevention, diagnosis and treatment. *Breast Cancer Management*, 4:41-51.

Leung, N., Furniss, D. & Giele, H. (2015). Modern surgical management of breast cancer therapy related upper limb and breast lymphoedema. *Maturitas*, 80: 384-390.

Leysen, L, Beckwee, D., Nijs, J., Pas, R., Bilterys, T., Vermier, S. & Adriaenssens, N. (2017). Risk factors of pain in breast cancer survivors: a systematic review and meta-analysis. *Support Care Cancer*, 25, 3607-3643. doi: 10.1007/s00520-017-3824-3.

Male, D. E., Fergus, K.D. & Cullen. K. (2016). Sexual identity after breast cancer. *Current Opinion in Supportive and Palliative Care*, 10, 1, 66-74.

Masia, J., Pons, G. & Nardulli, M. L. (2016). Combined Surgical Treatment in Breast Cancer-Related Lymphedema. *Journal of Reconstructive Microsurgery*, 32:16-27.

Mcwayne, J. & Heiney, S.P. (2005). Psychological and social sequelae of secondary lymphoedema: a review. *Cancer*: 1043:457-66.

Meraviglia, M. G. & Stuijbergen, A. (2011). Health-promoting behaviors of low-income cancer survivors. *Clinical Nurse Specialist*, 25, 118-124.

Mihara, M., Hara, H., Furniss, D., Narushima, M., Iida, T., Kikuchi, K., Ohtsu, H., Gennaro, P, Gabriele, G. & Murai, N. (2014). Lymphaticovenular anastomosis to prevent cellulitis associated with lymphoedema. *British Journal of Surgery*, 101:1391-1396.

- Moffatt, C.J., Franks, P.J., Doherty, D.C., Williams, A.F., Badger, C., Jeffs, E., et al. (2003). Lymphoedema: an underestimated health problem. *QJM: An International Journal of Medicine*, 92:731-38.
- Moffatt, C. & Pinnington, L. (2012). Facilitating development of community based lymphoedema services through clinical education. Project Evaluation Report, University of Nottingham and Derby Hospitals NHS Foundation Trust.
- Moffatt, C.J., Keeley, V., Franks, P.J., Rich, A. & Pinnington, L. (2017). Chronic oedema: a prevalent health care problem for UK health services. *Int Wound J*, 14, 772–781. doi:10.1111/iwj.12694.
- Morgan, P.A., Franks, P.J. & Moffatt, C.J. (2005). Health-related quality of life with lymphoedema: a review of the literature. *International Wound Journal*, 21:47-62.
- Mortimer, P. (2018). Cutaneous Manifestations of Edema. In Lee, B.B., Rockson, S. G. & Bergan, J. Eds. *Lymphoedema: A Concise Compendium of Theory and Practice*. Springer., Switzerland, pp.205-221.
- Neuner, J.M., Zokoe, N., McGinley, E.L., Pezzin, L.E., Yen, W.F., Schapira, M.M., & Nattinger, A.B. (2014). Quality of life among a population-based cohort of older patients with breast cancer. *The Breast*, 23, 609e61), doi.org/10.1016/j. breast.2014.06.002.
- Oppenheim, A.N. (1992). *Questionnaire Design, Interviewing and attitude Measurement*. Pinter Publishers. London.
- O'Toole, J., Miller, C.L., Specht, M.C., Skolny, M.N., Jammallo, L.S., Horick, N.,... & Taghian, A.G. (2013). Cording following treatment for breast cancer. *Breast Cancer Res Treat*, 140, 105–111. doi:10.1007/s10549-013-2616-9.
- O'Toole, J., Ferguson, C.M., Swaroop, N., Horick, N., Skolny, M.N., Brunelle, C.L., Miller, C.L.,... & Taghian, A.G. (2015). The impact of breast cancer-related lymphoedema on the ability to perform upper extremity activities of daily living. *Breast Cancer Res Treat*, 150, 381-388. doi:10.1007/s10549-015-3323-3.
- Pujols, Y., Seal, B. N. & Meston, C. M. (2010). The association between sexual satisfaction and body image among women. *J Sex Med*.72,2:905-916.
- Ramsden, A., Sharkey, A. & Furniss, D. (2015). Lymphaticovenular anastomosis improves quality of life in patients with secondary lymphoedema. *European Journal of Surgical*

*Oncology*: Association of Breast Surgery Conference and AGM (p. 41:40). Bournemouth, England: W.B. Saunders Ltd.

Ridner, S. H., Deng, J., Fu, M.R., Radina, E., Thiadens, S.R.J., Weiss, J., ... & Armer, J.M. (2012). Symptom burden and infection occurrence among individuals with extremity lymphedema. *Lymphology*, 45, 113-123.

Shaitelman, S. F., Cromwell, K. D., Rasmussen, J. C., Stout, N. L., Armer, J. M., Lasinski, B. B. & Cormier, J. N. (2015). Recent Progress in the Treatment and Prevention of Cancer-Related Lymphedema. *CA: A Cancer Journal for Clinicians*, 65:55-81.

Thomas, M., Morgan, K., Humphreys, I. et al. (2017). Managing chronic oedema and wet legs in the community: a service evaluation. *Nursing Standard*. 32, (11), 39-50. doi: 10.7748/ns.2017.e10951

Trusson, D. Pilnick, A., & Roy, S. (2016). A new normal? Omen's experiences of biographical disruption and liminality following treatment for early stage breast cancer. *Social Science & Medicine*, 151,121-129

Williams, A.F., Moffatt, C.J. & Franks, P.J. (2004). A phenomenological study of the lived experiences of people with lymphedema. *International Journal of Palliative Nursing*, 10:279-280.

**Table 1: Topic Guides**

<b>Topic Guide for pre-operative interviews</b>
Introduction and aims of the study
How long have you had lymphoedema? How long did you have swelling before it was diagnosed as lymphoedema? What do you have to do to manage your lymphoedema? How often do you have to do that? What is it like wearing compression garments every day?
How many episodes of cellulitis have you had? How does it feel to have cellulitis? What, if anything, do you need to do differently during an episode of cellulitis?
What effect, if any, does having lymphoedema have on Your work life? Your family life? Your social life? Your intimate relationships? On your finances?
How do you feel about the future of your health, having lymphoedema?
How did you feel when you first heard about the possibility of having Lymphatic Venous Anastomosis (LVA)? How did you feel when you discovered you qualified for LVA? How are you feeling about the prospect of having LVA?
<b>Topic Guide for post-operative interviews</b>
How are you?
Can you please tell me when you had your surgery? What did having the LVA procedure feel like? How did you feel straight after your surgery; and in the first few days afterwards? What difficulties, if any, did you experience after surgery? Has your lymphoedema changed in any way since having surgery? Are there any differences to how long you wear your compression garment since having the LVA procedure?
Have you had cellulitis since your surgery?
What difference, if any, has had the LVA procedure made to Your work life? Your family life? Your social life? Your intimate relationships? On your finances?
How do you feel about the future of your health since having the LVA procedure? Is there anything that you feel could be done to improve the service you received?



**Table 2: Participant data**

Pre-LVA interview Participant	Gender	Age	Site of Lymphoedema	Reason	Post-LVA interview participant
(01)	Female	40	Upper limb	Cancer	√
(02)	Female	67	Upper limb	Cancer	√
(03)	Female	61	Upper limb	Cancer	√
(04)	Female	65	Upper limb	Cancer	√
(05)	Female	67	Upper limb	Cancer	√
(06)	Female	36	Lower Limb	Cancer	√
((07))	Female	24	Lower Limb	Non-cancer	√
(08)	Female	37	Upper limb	Cancer	√
(09)	Male	62	Lower Limb	Cancer	√
(10)	Female	55	Upper limb	Cancer	√
(11)	Female	56	Upper limb	Cancer	x
(12)	Female	47	Upper limb	Cancer	x
(13)	Female	43	Lower Limb	Cancer	x
(14)	Female	74	Upper limb	Cancer	x
(15)	Female	76	Upper limb	Cancer	x
(16)	Male	50	Lower Limb	Non-cancer	x

Table 3: Themes and Subthemes

Pre LVA Theme	Subtheme	Quotes
<b>The Impact of Living with lymphoedema</b>	employment	<i>"It affects my job ... lifting. Now I've got an exemption certificate... to say I can't do it...coz...me arm's aching."</i> (10).
	Lifestyle practicalities	<i>"Doing chores, changing beds and things like that it takes me longer."</i> (05). <i>"Hand wash the socks from the night before, and then they go on the radiator or in the airing cupboard."</i> (06).
	Desires for the future	<i>"In the beginning I thought that my life was ruined because our life's ambition was we were going to live in Spain when we retired, and then they said you can't get sunburnt, you should avoid sitting out in the sun, and I thought what am I going to do for the rest of my life now?"</i> (11).
	Fear	<i>"Will the lymphoedema get worse, especially if it's on the same side? What happens if it comes on the other side and my other arm is affected?"</i> (01). <i>"It's an awful thing to live with, it's not a death sentence, but it's something that you have to live with for the rest of your life."</i> (15)
<b>Being Different</b>	Choices and limitations	<i>"It does limit certain things. I used to wear high heels an awful lot, and that's obviously curtailed because it's something that I know is going to exacerbate it."</i> (06).
	Physically altered	<i>"...I've always been a bit self-conscious, you don't want to see people taken aback or, being nice you know about this [lymphoedema]."</i> (02)
<b>Future Hopes and Emotions</b>		<i>. "Finding out about LVA... well, it is huge. Emotionally it is huge; I really felt very emotional."</i> (02). <i>"I don't want to get too excited about it because I don't want to be disappointed, you know if it doesn't change it."</i> (06).

Post LVA Theme	Subtheme	Quotes
<b>I am one of the lucky ones</b>		<i>"I feel very lucky to have had it." (08)</i>
<b>Returning to a former self</b>	Physical changes	<i>"my arm was less swollen, my arm was aching less it felt less heavy"(04)</i>
	Financial changes	<i>"I think I'm not so afraid of causing a problem...[I've] gone back to working four days rather than three..."(01)</i>
	Emotional changes	<i>"less worried about cellulitis. I've got two little rabbits at the moment, and they've got claws like needles, I think before I would have been having a meltdown."(02)</i>