

**The effect of compression garments on participation in life roles;  
experiences of women with breast cancer related lymphoedema.**

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March 2023

## Declaration

By submitting this research assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the author/owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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December 2023

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## **Abstract**

**Introduction:** Breast cancer is one of the most common cancers amongst women. Lymphoedema, a complication of breast cancer treatment, is often managed with a compression garment during maintenance phase that controls swelling which then improves function.

**Aim:** To explore the experiences of women with breast cancer-related lymphoedema about the effect of compression garments on their participation in life roles. Owing to the explorative nature of the study, no specific objectives were set.

**Method:** The study followed an interpretative phenomenological approach. Five participants were purposefully sampled from a population of 23. Virtual semi-structured interviews were used to gather data. Employing an interpretative phenomenological analysis framework, data for each participant was analysed separately, followed by cross case analysis and development of emerging themes.

**Results:** Four themes emerged: “Controlling the narrative”, “Braving the public”, “A double edged sword” and “Influence on mental health”. Controlling the narrative showed the need for choice of garment type, design and colour, wearing schedule, and around conversations about it. Braving the public focused on the attention the garment draws. A double edged sword showed that, while decreasing impairments and improving function, the garments were also a source of irritation. Mental health symptoms such as frustration on the one side and security on the other emerged.

**Conclusion:** The garments gave relief on an impairment level and supported activities and participation. However, accepting the compression garment as part of their lives for the rest of their lives was emotionally difficult. Participants were often not comfortable to appear in public with their compression garments because of the negative attention and emotions they created. They counteracted negative emotions by taking control.

**Key words:** Breast cancer, Choice, Compression garments, Breast cancer related lymphoedema, Participation in life roles, Social environment, complete decongestive therapy

## **Opsomming**

**Inleiding:** Borskanker is een van die algemeenste kankers onder vroue. Limfedem, 'n komplikasie van borskanker-behandeling, word hanteer met 'n kompressie-kledingstuk wat swelling beheer en gevolglik funksie verbeter.

**Doelwit:** Om die ondervindings van vroue met borskanker-verwante limfedem te verken wat betref die effek van kompressie-kledingstukke op hul deelname aan lewensrolle. Weens die ondersoekende aard van die studie is geen spesifieke doelwitte gestel nie.

**Metodiek:** Die studie het 'n interpretatiewe fenomenologiese benadering gevolg. Vyf deelnemers is doelgerig gemonster uit 'n populasie van 23. Virtuele semi-gestruktureerde onderhoude is gebruik om data te versamel. Deur 'n interpretatiewe fenomenologiese analise-raamwerk te benut is data vir elke deelnemer afsonderlik geanaliseer, gevolg deur kruisgeval-analise en die ontwikkeling van ontluikende temas.

**Resultate:** Vier temas het na vore gekom: “Beheer die narratief”, “Trotseer die publiek”, ’n Voordelige ergernis”, en “Invloed op geestesgesondheid”. Beheer die narratief het die noodsaaklikheid vir 'n keuse van kledingstuk-tipe, ontwerp en kleur, dra-skedule en gesprekke daar rondom getoon. Trotseer die publiek het gefokus op die aandag wat die kledingstuk trek. 'n Voordelige ergernis toon dat, hoewel die kledingstukke gestremdheid verminder en funksie verbeter, dit 'n bron van irritasie was. Geestesgesondheidskwessies soos frustrasie aan die een kant en sekuriteit aan die ander het ook te voorskyn gekom.

**Bevindinge:** Die kledingstukke bring verligting op 'n gestremdheid-vlak en ondersteun aktiwiteite en deelname. Dit was egter emosioneel moeilik om die kompressie-kledingstukke as deel van hul lewe vir die res van hul lewe te aanvaar. Deelnemers was

dikwels nie gemaklik om in die publiek te verskyn met hul kompressie-kledingstukke nie weens die negatiewe aandag en emosies wat dit skep. Hulle het negatiewe emosies teengewerk deur beheer te neem.

**Sleuteltermes:** Borskanker, Keuse, Limfededeem, Kompressiekous, Deelname aan lewensrolle, Sosiale omgewing

## **Acknowledgements**

Firstly, I give glory to my God who deserves it all. I would like to thank Surona Visagie for her assistance, support and wisdom through this journey, and my husband, my family and friends who supported me and always kept me positive.

## **List of abbreviations**

CANSA:	The Cancer Association of South Africa
IPA:	Interpretative Phenomenological Analysis
BCRL:	Breast cancer related Lymphoedema
CDT:	Complete decongestive therapy

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# Chapter 1

## 1. Introduction

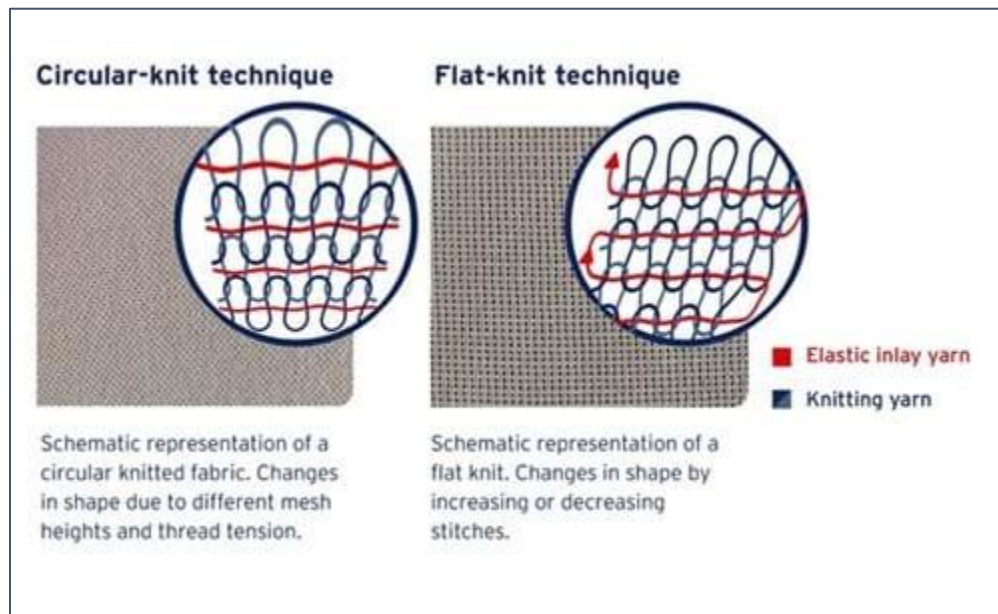
### 1.1 Background

One of the most common cancers that women are diagnosed with is breast cancer. According to the Cancer Association of South Africa (CANSA, 2022) 33.86 women per 100 000/year are diagnosed with breast cancer in South Africa. Women who are treated for breast cancer are particularly prone to lymphoedema and one in five breast cancer survivors has the possibility to develop lymphoedema (Longhurst, Dylke, & Kilbreath, 2018).

Lymphoedema is not a life-threatening condition, but it causes physical impairments such as fatigue, pain, discomfort, malformation, and heaviness in the affected arm. The impact of these impairments caused by breast cancer lymphoedema might be greater than the impairments themselves because it may lead to disability in different areas of functioning, as well as decreased participation in life roles and decreased emotional wellbeing (Bahtiyarca, Can, Ekşioğlu, & Çakıcı, 2019; De Groef, Van der Gucht, Dams, Evenepoel, Teppers, Toppet–Hoegars & De Baets, 2020). Participation in life roles includes personal and societal responsibilities, active and meaningful engagement, opportunity and access, control and choice, inclusion, and social connection, as well as having an impact on others (Hammel, Magasi, Heinemann, Whiteneck, Bogner & Rodriguez, 2009).

A well fitted appropriate gradient compression garment is the treatment often provided in the maintenance phase of lymphoedema. The garment can be either a compression glove, compression arm sleeve or both. It can also be maintained with a compression vest or jacket if lymphoedema is present on the chest area. Garments are either circular knit without a seam or flat knit and stitched together (Figure 1.1). Professionals that treat lymphoedema with lymphatic drainage are certified lymphoedema therapist and the professionals that usually fit compression garments are qualified orthotists. The focus of the current study was on compression arm sleeves. To achieve 24-hour compression the

compression garment is worn during the day while a softer sleeve is worn at night (Kligman, Wong, Johnston & Laetsch, 2004).



**Figure 1.1: Illustrating the difference between circular knit and flat knit compression garments (source: <https://www.lymphcare.com/na-en/products/how-different-compression-garments-work/flat-knit-or-circular-knit/>)**

Compression garments are effective in controlling lymphoedema. However, wearing compression garments can affect a woman's mental, physical, and psychological wellbeing as well as participation in life roles. It can decrease her confidence in public (Taghian, Miller, Jammallo, O'Toole & Skolny, 2014) and intimate relationships (Radina, Fu, Horstman & Kang, 2015). It influences her choice of clothing, leisure, and sport activities (Johansson, Ochalek & Hayes, 2020), as well as her ability to perform certain tasks and jobs (Smit, Coetzee, Roomaney, Bradshaw & Swartz, 2019).

## 1.2 Problem

Studies have shown that compression garments are effective in managing lymphoedema (Longhurst et al., 2018; Kligman et al., 2004). Adherence to compression garment

therapy and factors that influence adherence have also been explored in research (Al Onazi, Dolgoy, Parkinson & McNeely, 2020). Less is known about the influence of the compression garment on women's functioning, overall wellbeing, and participation in life roles.

### **1.3 Rationale and significance**

There is a need to understand women's experiences of compression garments and its influence on their participation in life roles to provide more focused and appropriate support in this regard. A better understanding of how compression garments influence participation in life roles might make service providers more sensitive to the experiences and the emotions women deal with when faced with this management strategy for lymphoedema.

### **1.4 Motivation**

Having had personal experience with lymphoedema and the wearing of daily, I have realized that it has influenced my wellbeing. For me it affected what I wear, how and where I exercise, and going to the beach. As a qualified orthotist/prosthetist and a certified lymphoedema therapist talking to the people I provide compression garment treatment for, further showed me how wearing compression garments can influence choices daily and how the experience and effect of wearing compression garments differ from person to person. Thus, I became interested in developing a better understanding of the effect that compression garments have on the lives of women wearing them and the experiences they have regarding the compression garment and how we as orthotists can help them with introducing this treatment into their schedule.

### **1.5 Summary**

One in five people have the possibility to develop lymphoedema after receiving treatment for breast cancer. Lymphoedema causes physical impairment that may lead to disability. Compression garments are used to manage lymphoedema. Wearing compression

garments can further limit or enhance participation. There is a need for service providers to understand the experiences of women wearing compression garments and the influences it has on their lives.

## **1.6 Layout of document**

Chapter 1 provided the study background, problem, and motivation. In chapter 2 literature relevant to this research assignment will be presented. It includes information about breast cancer-related lymphoedema, the role of compression garments in the management of lymphoedema, and the effect of compression garments on participation in life roles. Under methods and methodology in chapter 3 the study aim and study design will be discussed. More information on where the study took place and who the study population was and how sampling and recruitment happened, will be provided. Data collection and data analysis will be discussed, as well as the ethical considerations and trustworthiness of the research. Chapter 4 gives the participants' demographic information and presents the emerging themes from every participant separately. Chapter 5 provides a cross-case analysis of findings. Chapter 6 includes the discussion, while chapter 7 focuses on the conclusion, limitations, and recommendations.



## Chapter 2

### 2. Literature Review

#### 2.1 Introduction

The literature review focused on breast cancer-related lymphoedema, the role of compression garments in management of lymphoedema, and the effect of compression garments on participation in life roles. The following keywords were used in the literature search: “women OR female AND lymphoedema OR lymph

edema OR swelling OR oedema AND pressure garments OR compression garments OR compression therapy OR bandaging AND participation OR engagement OR function\* OR involvement OR quality of life.” The databases included were Google Scholar, PubMed, and EbscoHost that included the following sources: Academic Search Premier, CINAHL, Masterfile, Premier Nursing/Academic Edition, Medline, and GreenFile. Relevant literature included journal articles, dissertations, and books. There was a date restriction set for research done between 2000 and 2021 and filters that indicate the keywords in abstract.

#### 2.2 Breast cancer-related lymphoedema

The most common cancer among women is breast cancer and it is the second most common cancer globally (Ferlay, Colombet, Soerjomataram, Mathers, Parkin, Piñeros, Znaor & Bray, 2019). Surgery is the primary intervention for the management of breast cancer and other treatments include chemotherapy and radiation therapy, immunotherapy, and hormonal treatment (Vanderpuye, Grover, Hammad, PoojaPrabhakar, Simonds, Olopade & Stefan, 2017). A long-term health problem that breast cancer patients face, is lymphoedema.

Lymphoedema is not a curable condition and can arise years after treatment for breast cancer has been completed. Lymphoedema is a build-up of fluid in the arm or truncal

area caused by a disruption in the lymphatic system. It can be the result of radiation therapy that damaged the lymph nodes in the axilla, an axillary lymph node dissection, or advanced cancer. A critical review of the literature where 50 studies were included representing 67000 women indicated that 19% of breast cancer survivors are affected by breast cancer-related lymphoedema (BCRL) in follow-up more than a year and less than two years after treatment (Shah, Zambelli-Weiner, Delgado, Sier, Bauserman & Nelms, 2020).

On an impairment level breast cancer-related lymphoedema can cause discomfort (Bahtiyarca et al., 2019), pain (Thomas-MacLean, Miedema & Tatemichi, 2005), numbness (Thomis, Devoogdt, Bechter-Hugl, Nevelsteen & Fourneau, 2020), swelling and malformation of the arm (Bahtiyarca et al., 2019), as well as decreased range of movement (Thomis et al., 2020). These impairments lead to decreased upper limb function and difficulties with performing daily activities (Bahtiyarca et al., 2019; De Groef et al., 2020; Thomis et al., 2020; Zhao, Wu, Zhou, Li, Li & Chen, 2021), housework, gardening (Thomas-MacLean et al., 2005; Zomkowski, Wittkopf, Back, Bergmann, Dias & Sperandio, 2020) and the ability to earn a living (Buki, Rivera-Ramos, Kanagui- Muñoz, Heppner, Ojeda, Lehardy & Weiterschan, 2021). This leads to disability (Thomas-MacLean et al., 2005), reduced quality of life, decreased ability to participate in society, and decreased well-being (De Groef et al., 2020). Lymphoedema influences the sense of self-value negatively (Zhao et al., 2021). Watts and Davies (2016) found that it is difficult to get appropriate clothing that fits over the arm and the compression garment. Buki et al (2021) who did a qualitative study through semi-structured interviews with 10 Latin women with breast cancer-related lymphoedema indicated that women with breast cancer-related lymphoedema experience financial stress due to loss of income because they are unable to work, and this affects psychological well-being. Some breast cancer survivors decide to sacrifice their social life to prevent people from asking questions about their swollen arm or compression garment.

### **2.3 Role of compression garments in management of lymphoedema**

The main goal in management of lymphoedema is to keep the swelling down, restore the function of the swollen limb, reduce the possibility of infection, and improve quality of life (Bahtiyarca et al., 2019). According to the International Society of Lymphology (2013), the gold standard treatment for lymphoedema is compression therapy. Lymphoedema cannot be cured but can be successfully managed with compression garments.

A quantitative survey was done by Miller (2018) between October 2015 and March 2016 in 21 medical stores in Germany and two in Norway where a total of 133 participants enrolled. All the participants rated the overall importance of the compression garment relatively high. The fit of the compression garment was seen to be more valuable than the outer appearance. The correct fit improves overall wear and comfort, does not restrict mobility, and assists in functioning through controlling the lymphoedema (Miller, 2018).

Based on a critical review by Shah et al (2020) early recognition of lymphoedema can be used to trigger interventions, involving manual lymphatic massage, compression garments, and physical therapy to prevent a severe state of lymphoedema. Prevention measures and management of lymphoedema improve the quality of life and reduce the public health burden of chronic breast cancer-related lymphoedema in breast cancer survivors.

### **2.4 The effect of compression garments on participation in life roles**

According to Miller (2018), who did an observational study (n=133), women experienced less limitations in function when wearing their compression garments versus when they were not wearing them. However, Smit et al (2019) discovered in a systematic review and meta-synthesis of 180 studies that women still felt limited in their daily activities when wearing compression garments. Activities like housekeeping, hobbies, and professional practice were hampered by the compression garment. Housekeeping activities like cooking and cleaning, ironing, and folding the laundry were also hindered.

Participants had trouble in opening and closing buttons of a shirt, answering a telephone, writing and computer use.

A targeted literature review done from four studies which were published before the 1<sup>st</sup> of May 2020. showed that physical activity is linked to increased physical and psychosocial health and greater social support in breast cancer survivors. However, the reviewed studies also showed that not many breast cancer survivors are participating in physical activity (Johansson et al., 2020). Where lymphoedema was controlled with the use of a compression garment, participants could participate in physical activity. However, wearing a compression garment influenced the choice of leisure and sport activities that were pursued (Johansson et al., 2020). Wearing of compression garments was also connected to increased participation in physical and social environments according to a sequential mixed methods study which was done with an online questionnaire followed by a structured interview with seven dragon boat teams (n=11). Nine of the 11 participants were breast cancer survivors (Fong, Saxton, Kauffeldt, Sabiston & Tomasone, 2020).

According to a review done by Taghian et al (2014), wearing of compression garments was connected to decreased confidence in public. It influences the clothing styles that women choose to wear (Johansson et al., 2020).

Radina et al (2015) did a cross-sectional study with a mixed-method approach to collect qualitative and quantitative data. Of a total of 348 breast cancer survivors who enrolled in the web-based study, 176 suffered from breast cancer-related lymphoedema. Seven participants in this study reported that compression garments restricted physical intimacy. It was seen as a barrier to sexual activity. One participant felt that the compression garment slows down the intimacy process because it takes time to remove the compression garment. Another participant felt it is difficult to have intercourse when wearing her night garment.

## **2.5 Conclusion**

While much is known about the effect of lymphoedema on women's participation in life roles, and the value of compression garments as intervention for lymphoedema, less information is available on the role of the compression garment in their participation. This study will add some information to address this gap through exploring the question, "What are the experiences of women with breast cancer-related lymphoedema regarding the effect of compression garments on their participation in life roles?"

## **Chapter 3**

### **3. Methodology and Methods**

#### **3.1 Introduction**

This chapter presents the aim of the research assignment and how the results were achieved. An interpretative phenomenological design was chosen because the main objective was to explore and interpret lived experiences. Samples in IPA are small and therefore I chose a small sample through purposive sampling. I could carefully pick a homogenous group of participants from whom data was collected through online semi-structured interviews. Finally, analysis strategies, trustworthiness and ethical considerations are presented.

#### **3.2 Study Aim**

The study aim was to explore the experiences of women with breast cancer-related lymphoedema regarding the effect of compression garments on their participation in life roles. Owing to the explorative nature of the study, no specific objectives were set.

#### **3.3 Study Design**

The study was situated in qualitative constructivism. An Interpretative Phenomenological Analysis (IPA) design was used. IPA is useful to explore experiences or behaviours that are not understood sufficiently and explain them from the perspective of those directly involved. The phenomenon is presented through rich descriptive data. IPA is based on the concepts of phenomenology (personal experiences), hermeneutics (interpretation), and ideography (understanding an experience from a particular perspective in a particular context) (Pietkiewicz & Smith, 2014). In the current study, women with breast cancer-related lymphoedema, living in a specific context, shared their lived experiences regarding the role that compression garments play regarding participation in their life

roles. Their experiences were then further interpreted during analysis (Pietkiewicz & Smith, 2014).

### **3.4 Study Setting**

Cape Town is home to some 4.4 million people, where 4.7% of South Africans five years and older were classified as disabled (The City of Cape Town Metropolitan Municipality, 2020). The City of Cape Town is situated in the southern Peninsula of the Western Cape Province in South Africa. The exact incidence of women diagnosed with breast cancer-related lymphoedema in the Western Cape is not known (Meneses & McNees, 2007).

Study participants have all received compression garment treatment at a private health care orthotics and prosthetics practice situated in the Sea Point Medical Centre that belongs to the me as the researcher and where I practice from. Patients treated at the practice lives all over Cape Town and come from areas like Bellville, Durbanville, Panorama, Diep River, Constantia, the Atlantic Seaboard, and Central Cape Town. They received cancer treatment from Cancercare centres in Rondebosch or Panorama. Others received their treatment from Netcare Christiaan Barnard Hospital or Life Vincent Palotti Hospital. These centres are in a radius of 10km-40km from the practice.

### **3.5 Study Population, sampling, and recruitment**

The study population consisted of the 23 women with breast cancer-related lymphoedema who received compression garment treatment, at a private clinic, in Cape Town, South Africa, between 01 September 2018 and 31 August 2021. To ensure a homogenous group of participants as required for IPA (Pietkiewicz & Smith, 2014) specific in- and exclusion criteria were implemented:

### **Inclusion criteria:**

- The women must live in the City of Cape Town. Climatic factors (e.g. temperature differences and humidity) can influence their experiences when wearing compression garments (Thomas-MacLean et al., 2005).
- Women older than 18. Breast cancer is uncommon in children (Gutierrez, Housri, Konjaris, Fischer & Sola, 2008).
- Participants fluent in Afrikaans and/or English and/or isiXhosa, the three languages most spoken in the Western Cape province.
- Women who have access to a virtual platform (android phone or computer) as data was collected through synchronous virtual interviews.

### **Exclusion criteria:**

- Women in the decongestive phase of treatment. Compression bandages, rather than compression garments, are used in the decongestive phase to reduce swelling (Maree & Beckmann, 2016).
- Women wearing a compression wrap. The wrap is an inelastic pressure system and not the same as a flat knit or circular knit compression garment (De Sire, Fusco, Sajjadi, Lippi, Cisari & Invernizzi, 2021).
- Women with lymphoedema due to something other than breast cancer.

### **Sampling Strategy:**

A sampling strategy is a method to systematically select a smaller number of participants from a population that was pre-defined to take part in a study (Sharma, 2017). The strategy chosen for the study was purposive sampling. Purposive sampling requires access to key information that can guide sampling of participants who can share rich and unique experiences (Lloyd, Briggs, Kane, Jeyarajah & Shepherd, 2014) as required in IPA (Pietkiewicz & Smith, 2014).



Samples in IPA studies are usually small because the comprehensive case by case analysis that is required is time consuming. The focus is to provide an in-depth exploration of the phenomena, rather than creating theory that needs to be generalized over a population (Pietkiewicz & Smith, 2014). Pietkiewicz and Smith (2014) indicate that sample size can vary between one and 15 in an IPA study. Five persons were sampled for the current study. A sample of five offers insight into specific experiences and allows for the exploration of similarities and differences amongst participants while the volume of data does not become overwhelming (Pietkiewicz & Smith, 2014; Smith, Flower & Larkin, 2009).

After ethical approval was received by the Health Research Ethics Committee of Stellenbosch University, sampling and recruitment took place. I am the owner of the practice, and I accessed the data that was stored on the practice's patient records system to develop a sample frame of women that adhered to the inclusion criteria. The sample frame contained information on age, marital status, employment status, type of compression garment and how long they have been wearing the garment (Appendix A). The practice had a patient and practice agreement in place. The agreement included the POPI Act requirements, and that data can be used by the practice as per approval given by the patient. I sampled eight potential participants from the sample frame of 15 (see table 3.1).

With purposive sampling, bias can easily occur. Therefore, clear sampling criteria should be presented (Sharma, 2017). The following criteria were taken into consideration:

- Different ages
- Differences in marital status
- Differences in employment status
- Different types of compression garments (flat knit or circular knit)
- Different lengths of time wearing the compression garment

**Table 3.1: Breakdown of population, excluded criteria, sampling, and number of participants.**

Total population	23
Excluded: Lived outside of Cape Town	6
Passed away	2
Sample frame	15
Number sampled	8
Number consented and participated	5

### **Recruitment strategies:**

After sampling, one of my employees contacted the sampled individuals telephonically, explained the study in full and received verbal consent from those willing to participate in the study. I emailed the informed consent document (see Appendix B) to those who provided verbal consent. Out of 8 participants who were initially sampled, 5 returned the signed informed consent document, and I contacted them again to make an appointment for an interview at a time that was convenient to them.

### **3.6 Data collection strategy and tools**

Face to face semi-structured interviews are the most suited data collection method in IPA studies as they allow the collection of rich data (Pietkiewicz & Smith, 2014), an important part of IPA. In the current study, as we were still in the aftermath of COVID-19 during data collection, data was collected by me through synchronous, virtual interviews, on Zoom or WhatsApp video call. The data collection strategy was practised through role play and a pilot study as described by Hunt, Chan and Mehta (2011).

I used broad, open-ended questions to allow the participants to share their experiences and developed their responses into a conversation (Lindsay & Schwind, 2016). An interview guide (Appendix C) was used. I developed the interview guide with support from my supervisor and colleagues. It was further refined through a pilot study. It was important to see it as a supportive tool for reference to provide guidance to the discussion (Reid & Mash, 2014). The interview schedule consisted of predetermined open-ended questions supplemented by probes and prompts that assisted participants to share their experiences. I started the interview with questions about wearing compression garments for lymphoedema to launch the conversation. Then I went into more profound questions about the experience and effect of wearing compression garments for lymphoedema. My questions went further into functioning and participation in life roles (O'Leary, 2017).

Although two interviews per participant were proposed, only one interview was done with each participant as provisional analysis showed that sufficient data to address the study aim was collected during this interview (Solomon, Nixon, Bond, Cameron & Gervais, 2020). According to Pietkiewicz and Smith (2014), the duration of most IPA interviews is 60 minutes or longer. In this study the interview length varied between 40-90 minutes and gave me enough time to gather rich, in-depth data (Reid & Mash, 2014).

The interviews were in English. Participants were given a choice of English, Afrikaans or IsiXhosa, but all chose to do the interviews in English. I recorded the interviews with a voice recorder and a backup recording device. I stored the data in a password-protected file on my computer and a password-protected external device.

Demographic information was captured from the practice data base onto a spreadsheet (see Appendix D for an example). The information included age, employment status, marital status, type of compression garments worn and length of time wearing the compression garment. I confirmed the information on the spreadsheet with the participants before I started with the interview.

### **3.7 Data analysis strategy**

I used an interpretative phenomenological analysis (IPA) approach. In IPA both the researcher and the participant's interpretation are considered during analysis (Pietkiewicz & Smith, 2014). IPA is about phenomenology and trying to understand the participants' lived experiences and how they make sense of their own experiences (Smith et al., 2009). It is also about interpretation and the researcher making sense of the data to develop insights that the participant might not be aware of. Finally, IPA is idiographic with individual cases being analysed and explored separately before general similarities and differences are explored across participants (Pietkiewicz & Smith, 2014).

The recordings were transcribed by me. Each participant's data were analysed separately before doing a cross-case analysis. For analysis I printed the transcribed interviews on the middle third of a page. During reading of the transcripts, codes were identified and highlighted with the use of coloured markers. In the left-hand column, I wrote explanatory comments, reflections, and observations from the data as I read the transcripts. In the right-hand column, I wrote down provisional emerging themes (Visagie & Schneider, 2014). The process aimed to distil the codes and comments into themes. The next step was to find connections between the codes/emerging themes and group them according to similarities. Codes were grouped into mutually exclusive themes.

Once data for each participant were analysed and written up, cross case analyses were done. Cross case themes were developed through creating a table with each participant's themes that corresponded with one another and their direct quotes. I then decided on a theme that encompassed the meaning of the individual themes. When I wrote about the study, the themes identified were defined and characterized with extracts from the interviews followed by my analytical comments (Pietkiewicz & Smith, 2014).

My supervisor, who is an expert in qualitative research and has experience of IPA, gave feedback on the pilot interview, assisted with the provisional analysis after the first interview, and identified issues which needed to be further explored and also assisted

with identification and refinement of themes in the other interviews and during cross case analysis. This enhanced the credibility of the findings (Nowell, Norris, White & Moules, 2017).

### **3.8 Pilot Study**

I did a pilot study with a member of the study population to determine the soundness of the proposed methods and if I had to make any changes. The pilot study showed whether the interview questions were clear and acceptable. It was useful and assisted me to prepare for the interview and determine if I was ready and capable to do the interviews. Finally, it helped me determine if the data collected would answer the study question (Kim, 2010). The pilot study showed that the initial questions were too theoretical in nature. I made changes to the interview schedule and therefore the pilot study was not used as data source in the final analysis.

### **3.9 Trustworthiness**

Trustworthiness is one-way researchers can motivate that the study and findings are worth it. I addressed the four concepts of trustworthiness namely credibility, transferability, dependability, and confirmability (Nowell et al., 2017).

#### **3.9.1 Credibility**

A study is credible when the described experiences are recognized by the readers, and the conclusion matches the reality. To increase credibility, I did purposive sampling, used an interview schedule, and individual followed by cross case analysis. My supervisor assisted me with the development and refinement of themes. I did not do member checking as transcriptions were checked for correctness by my supervisor and I. At later stages the findings included my interpretations which might have made participants uncomfortable (Morse, 2005).

### 3.9.2 Transferability

To support transferability, I did purposive sampling by selecting potentially 8 appropriate participants that have knowledge on the topic and can provide in depth data about their experiences. I provided detailed descriptions of the methods, setting, and demographic information of the participants (Nowell et al., 2017). This should allow readers to compare the findings with their own context to judge the transferability of the findings or recommendations (Nowell et al., 2017).

### 3.9.3 Dependability

The formulation of the research proposal, which received ethical approval, enhanced dependability. I provided detailed descriptions, discussed limitations, and presented the research findings in a clear manner so that the decisions and choices can be followed by another researcher (Nowell et al., 2017). I also did a pilot study. I kept a reflective diary throughout the study which can enhance dependability as well as confirmability.

### 3.9.4 Confirmability

To ensure confirmability of the study, the interpretation was based on the data, rather than on my experience, bias, or interests (Nowell et al., 2017). When credibility, transferability and dependability are achieved, confirmability is enhanced. Direct quotes from participants to support themes are included (O'Leary, 2017). I demonstrated how I reached my conclusions and how I determined the interpretations and reasons for the theoretical, methodological, and analytical choices throughout the study so that others can understand how and why I made certain decisions (Nowell et al, 2017).

Throughout the study I kept a reflecting journal. I was aware that my insider experience as someone who wore a compression garment for lymphoedema, my clinical knowledge on compression garment therapy, and my dual role as clinician and researcher was a potential threat to trustworthiness and held ethical implications. This insider position assisted me to build trust and collect rich, nuanced data. However, it could introduce bias

if I allowed my experiences and perceptions to cloud that of my participants or if participants provided information that they thought would please me. I remained aware of this and actively sought to prevent it. I documented my thoughts and experiences in a reflective journal that assisted me to keep an open mind so that I could explore and share participants' stories (Berger, 2015). I realised how the participants experienced the same type of difficulties in their own ways and how their compression garments had to become part of their journeys for them to accept them. It was an enriching experience for me to look at their experiences through the lens of a researcher and to listen to their struggles and how they need to deal with them to keep on participating in society and in their daily activities.

### **3.10 Ethical considerations**

The study started once ethical approval was obtained from the Health Research Ethical Committee at Stellenbosch University (Nr: S21/11/243). The three main ethical principles of beneficence/non-maleficence, respect for persons (dignity and autonomy), and distributive justice (equality) as stipulated in the South African Department of Health's Ethics in Health Research document (RSA, 2015) was adhered to. Even though the participants did not benefit directly, their experiences may benefit future patients. There might have been psychosocial benefits from talking about and sharing their experiences.

#### **3.10.1 Beneficence and non-maleficence**

With respect to non-maleficence, the interviews did not put participants at any physical risk. I offered to pay for the data participants would use to take part in the study. However, all participants had wifi and told me it was not necessary to pay for their data usage. The questions allowed the participants to share their experiences and they were not forced to share anything which they were not comfortable sharing. Participants did not experience emotional reactions during the interviews. They felt they could share experiences that they normally could not share with anyone else. Through the study they had someone that listened to them.

It was important to protect the anonymity of the participants and including direct quotes can lead to participants being recognized by themselves or others even when all personal information has been removed. Participants provided consent for their data to be shared in journal articles and for it to be shared with supervisors and examiners.

It is important that I prevented role confusion that can happen between me being the researcher and the primary therapist and this could put the participants under pressure to participate in the research. It was therefore important that I gave extra care to the issues of coercion, deception through misrepresentation, and attention to moral problems in the research process (Hewitt, 2017). A fellow employee made the initial contact with the participants. This employee was not known to the participants as she was newly employed at the practice. She gave the participants the opportunity to think about the study and respond at a later stage whether they wanted to take part in the research, instead of asking for an immediate answer.

All data was kept confidential. Transcripts was anonymised. Recordings and transcripts were stored in a password protected computer file and a cloud backup. Hard copies of transcripts were stored in a locked cupboard.

Participants each received a gift voucher of R200.00 to express my gratitude to them for their participation in the study.

### 3.10.2 Distributive justice (equality)

With regards to social justice, all the participants that received compression garments and adhered to the inclusion criteria formed part of the population for the study. Each participant had an equal opportunity to share their experiences. The participants had access to the internet; they also had access to a virtual platform, either a telephone or a computer.



### 3.10.3 Respect for persons (dignity and autonomy)

In research, respect for autonomy is dealt with through informed consent. This was the agreement that was given voluntarily by the participant to take part in the research and to receive information regarding the nature of the study. Consent was given without any threats or any encouragement. The participants had the mental competence to give consent (Hewitt, 2007). The power imbalance of me being the treating therapist and the researcher was an important threat to autonomy in this study. The participants were clearly informed that refusal to participate, or withdrawal from the study, would not have any effect on their future treatment or the patient–therapist relationship. The consent form gave potential participants an overview of the focus and methods of the study and also indicated that participation was a voluntary decision. The consent form and the interview were in a language chosen by the participant. The participants could withdraw at any given stage. Participants completed the consent form before I proceeded with the study.

## 3.11 Summary

It was important to make sure that the participants felt they could share their experiences in a trusted environment in this IPA study. Semi-structured interviews took place on a virtual platform with five purposively sampled participants. Trustworthiness was sought. The three main ethical principles of beneficence/non-maleficence, respect for persons (dignity and autonomy), and distributive justice (equality) was always adhered to.

## Chapter 4

### 4. Individual findings

#### 4.1 Introduction

As per IPA methods the data was analysed separately and then across participants. The findings are then also presented first separately in this chapter and then across cases in chapter 5. Participant ages ranged from 46-58 and they have been wearing compression garments for between less than 1 and 8 years.

**Table 4.1: Participants' demographic information**

	<b>Age</b>	<b>Marital status</b>	<b>Employment status</b>	<b>Type of garment</b>	<b>Wearing garment since</b>
<b>Anne</b>	52	Married	Unemployed	First circular knit then flat knit	March 2020
<b>Sophie</b>	47	Married	Employed	Flat knit	Jan 2022
<b>Mary</b>	46	Married	Unemployed	Flat knit	2018
<b>Abby</b>	46	Married	Employed	First circular knit then flat knit	2015
<b>Clare</b>	58	Unmarried	Employed	Flat knit	Oct 2022

Figure 4.1 provides an overview of the themes that were developed from the data. The names used for participants are pseudonyms rather than their given names to maintain confidentiality.

Anne	<ul style="list-style-type: none"><li>•Theme 1: "A nuisance"</li><li>•Theme 2: "That's not dressy"</li><li>•Theme 3: "Frustration"</li></ul>
Sophie	<ul style="list-style-type: none"><li>•Theme 1: "A double edged sword"</li><li>•Theme 2: One of the team</li><li>•Theme 3: Schedule</li></ul>
Mary Ann	<ul style="list-style-type: none"><li>•Theme 1: I can do everything and more</li><li>•Theme 2: Consider it maintenance</li><li>•Theme 3: "Security and Protection"</li><li>•Theme 4: People's reaction to the garment</li></ul>
Abby	<ul style="list-style-type: none"><li>•Theme 1: "Controlling the narrative"</li><li>•Theme 2: Finding the right garment</li><li>•Theme 3: Service provider, my cheerleader</li><li>•Theme 4: Corporate culture</li><li>•Theme 5: "A Journey"</li></ul>
Clare	<ul style="list-style-type: none"><li>•Theme 1: Building confidence</li><li>•Theme 2: "Yeah, it sucks"</li><li>•Theme 3: The unknown</li><li>•Theme 4: Wearing it in public</li></ul>

**Figure 4.1: Overview of emerging themes per participant**

## **4.2 Participant 1: Anne**

Anne, an unemployed mother of a physically impaired child, was diagnosed with lymphoedema in 2017 and started wearing compression garments in 2020. Three themes emerged from the interview with Anne. These were, 'A nuisance', 'That's not dressy' and 'Frustration'.

### **4.2.1 Theme 1 "A nuisance"**

Anne felt that the compression garment was a necessity and she called it her partner in a resigned way. But she also saw the compression garment as a drag, an annoyance.

Nothing big, but an irritant curtailing her in numerous small ways: from household tasks to the choice of clothes, from spontaneous interaction to planned trips and vacations. Her narrative tells the story.

“It’s helping but it’s not that comfortable...It is inconvenient, and it is for me a nuisance; I must like always remember to put it on, or must remember to pack it when going somewhere, or when sleeping somewhere for the week ... say I go on holiday I must take this thing, like everywhere I go, I must have this thing with me ... Yeah, this thing that’s always going to be with me. My partner ... It’s always going to be a part of me ... I won’t be able to do without it. Like it’s chronic medication.”

The reference to chronic medication showed that she knew the garment is a permanent addition to her life. But this knowledge did not sit well with her. Her narrative showed frustration, and irritation with the garment through referring to the compression garment as ‘this thing’ on numerous occasions.

“...I always have to worry about this thing ... I have to wear this thing forever. Move past, or get over, or whatever, but it’s always going to be a part of my daily [life]. Oh, I have to wear this thing. I have to wear this thing. So, like, before I could do whatever I wanted to do, however I wanted to do it. Now I have to be cautious with what I do. Or I’m gonna have to do everything with this thing on from now on ... To be honest, [I] would rather just not wear it.”

Anne was positive that the garment helped her through reducing tightness, swelling and pain in her arm, providing protection against the sun, and acting as a signal to others that her arm is bothering her.

“There have been times where I have to wear it two or three days in a row, then it does help. It really does help.”

“...they don’t always see me wear it. But when they see me wear it, then they know, okay, your arm is not feeling right ... and then they know they must help.”

But her choice of words also indicated a reluctance to wearing it, even a resistance to the garment as shown by phrases like, “I must wear it ... Why must I wear it? ... It must be part of my life ... I must take this thing everywhere I go” occurring throughout the transcript.

#### **4.2.2 Theme 2 “That’s not dressy”**

Anne disliked wearing the sleeve in public and chose not to wear it when in community settings: “I won’t wear that outside because it’s ... you’re a woman. That’s not dressy.”

When symptoms in her arm necessitate that she wears it, she prefers to wear a compression garment that has less of a medical appearance.

“... sometimes then my arm is bad. I need to wear it. I will wear it ... the blue one looks like there is a problem so then people, more people could possibly stare. So, then I try to avoid that one more because it doesn’t have the print or a design. It actually does look medical and there’s a problem ... I will wear the one with the design ... if I’m forced to wear it for a reason, but still wear something that will [cover it].

As indicated above, she will go to some length to hide or make the compression garment less obtrusive.

“I’ll try maybe to wear something that [it] doesn’t have to show ... [If] I was forced. Oh God. If I’m, if, if I was able to come to a point where ... that I have to wear it every day. I most probably then make sure, um, to wear something [in summer], uh, a shirt that has a long ... that chiffon or you know or a waterfall thing that’s light.”

Her dislike of the garment went as far as making contingency plans in the instance of photos to make sure the garment will not be captured in the picture. This might be due to her placing value on looking put together and well groomed.

“And if I need to take photos, stand with my arm behind someone. No one will see it. I already have all that planned. If ... they say stand here and I say no. Let me stand this side and then I put my arm behind someone ...”

The curiosity of others might have played a role in her reluctance to wear the sleeve in public. She disliked the attention and questions it drew. And she might find it less trying to not wear the sleeve than to enter into explanations about it.

“So, with the sleeve as well, it's almost like now it's going to draw even more attention ... people stare man. I don't like that ... Or more people could ask ...”

#### **4.2.3 Theme 3 “Frustration”**

Anne claimed that wearing the compression garment was ‘not an emotional thing’ and that it did not ‘get her down’. But she acknowledged being frustrated with the garment on more than one occasion. In fact, words like frustrated, frustrating, or frustration were mentioned 20 times in the narrative and have thus become a theme through numeration.

“I won't like get emotional in the sense I will cry or anything like that, I will just be frustrated.”

“Like it's not like a bad thing, it's just frustrating, like frustrating that I'm so limited then I uhm I just feel so how do you say ‘dik’ [had enough].”

“So, yeah there is just ... have a feeling of frustration, man.”

She said she did experience some depression after receiving the garment initially.

“... in the beginning like it was it was a bit depressive in a way because I had to live with this thing.”

While realising that accepting the compression garment as part of her life might aid the prevention of depression, she was not ready to take that step.

“To stay out of a depressive state and all of that, I just learned to live, to find a way, to not accept it, but just ...”

#### **4.2.4 Conclusion**

Anne saw her garment as a lifelong partner but also as a nuisance. She did not enjoy wearing it and disliked the negative attention it caused when she was in public. She wore it when she felt it was necessary, but not daily. It influenced her clothing choices and donning and doffing the garment caused frustration. She realised the importance of accepting the compression garment for her overall wellbeing.

#### **4.3 Participant 2: Sophie**

Sophie was diagnosed with lymphoedema in 2022 and started wearing her compression garment after her diagnoses. During the analysis three themes emerged. Polarization was seen in the two subthemes under theme 1, ‘A double-edged sword’, with the ‘security’ provided by the garment during participation on the one side and the ‘unwanted attention’ it draws on the other. Two other two themes were, ‘One of the team’ and ‘Schedule’.

##### **4.3.1 Theme 1: “A double-edged sword”**

Sophie felt her garment was providing support and kept her swelling under control. But she also felt that it singled her out, made her different. She chose to hide it from colleagues at work since she did not want to be treated differently. It influenced her clothing choices, and she felt it drew negative attention, but it also allowed her to be active with confidence.

“... it's a bit of a, a double-edged sword for me ... it makes me feel vulnerable, but also confident if that makes sense ... I find I feel much more confident if I'm doing any form of exercise with it on, if I know I'm going to be doing things at home, I will put it on for definite ... I don't have to think about what I'm doing [when wearing

the garment]. But, um, uh, emotion, emotionally, just, it does open, uh, room for people to question.”

**Security:** Physically it keeps the swelling down and that provides her with the security to do what she wants to do, to be free when she exercises. She vocalised the sense of security that wearing the garment created for her enthusiastically.

“... it's the assurance that I know that if I'm going to gym and I throw my arms up in the air, I'm not going to have a problem ... Basically the fact that I know that I can push that little bit harder when I do wear it, like go up the mountain, walking on hikes and things like that. I don't have to be as cautious, when I pull myself up on things: that to me is a huge advantage.”

“Maybe it's giving me a full security when I wear it, <laugh> if that makes sense. But, um, yeah ... I feel safe with it. The difference is absolutely amazing. Um, I don't think I would, uh, consciously be able to live without.”

And she knows the change when she does not wear the garment.

“I can tell you the difference is amazing. So even just being at the office and if I don't wear my garment, like I can feel now my arm is a little, um, uh, tingles ... I mean, it's like a, a slightly painful tingle because I didn't wear my garment. So, this is just from using my mouse.”

**Unwanted attention:** On the other hand, Sophie explained that she did not want others to feel sorry for her or treat her as different. When visible the garment can lead to a conversation about her cancer and thus lead to sympathy. Therefore, she chose for the garment not to be visible in public. She will either not wear it or cover it with clothing.

““I don't mind talking about it [having had cancer]. I just don't want any[body] to feel sorry for me ... if I wanted attention, it [the compression garment] would create [it] ... I'll only wear it if I'm wearing a long sleeve top. I won't wear it if I'm



wearing a short sleeve top ... even if my family or friends come around, I'll take it off."

#### **4.3.2 Theme 2: One of the team**

Sophie wore her garment daily until she started a new job. Because she was not ready to share her diagnoses with her colleagues as she felt they would see and treat her as different; she did not wear the garment to work if it was not covered.

"Um, I was wearing it every day before I went to work. But since I've been at the office, I don't wear it if I'm wearing short sleeve tops. Because nobody at the office knows that I've had cancer ... I don't want anyone to feel sorry for me or treat me any differently. So that's why I don't talk about it or whatever. So only he [employer] knows, but nobody [else] knows. So, I don't wear it every day, but if I wear a long sleeve top, I do wear it on the day ... I think they've seen it, but they don't ask because you can see it out the bottom of my sleeve a lot of the times. And I don't, I won't pull my sleeve down, but, um, I won't walk around with it on."

Sophie did not want to be singled out. She also wanted to control decisions about what she could and could not do. This seems like a personal choice, but it might be that she was worried about being seen as not doing her part and that that might influence relationships or even her employment and/or promotion opportunities.

"I just don't, I don't want them to think, oh, she can't do this, she can't do that because that's where I start feeling upset with myself. Oh, if someone doesn't ever tell me that I can't do something, number one, because nobody tells me what to do, <laugh> but, um, like for instance, at the office we did a stock take. It was my first stock take there. And if they included everybody in the whole company and we had to move boxes and I was wearing a long sleeve that day, if I wasn't wearing a long sleeve and wearing my garment, I wouldn't have been, I wouldn't have done it."

### **4.3.3 Theme 3: Schedule**

Sophie felt that the garment had to work for her and fit with her lifestyle. She developed a wearing schedule, based on her needs. But ensuring the amount of time she wore the garment was sufficient for it to perform its function.

“So, I wear it in the morning to the afternoon ... I still check my time, like when it gets to five or six, unless I'm doing any exercise, I'll take it off ... But you know I associated it with like work, like a job ... That's it. Yeah. So, it's like <laugh>, but I wear it on the weekends as well. So, it's a weekend job.”

### **4.3.4 Conclusion**

The garment gave Sophie confidence to participate in life roles and activities important to her. But she did not want to be seen as different or that she was not capable of doing certain activities at work and either did not wear it to work or hid it with clothing. She took control of the wearing schedule and made it fit in with her lifestyle.

## **4.4 Participant 3: Mary**

Mary was diagnosed with lymphoedema in 2018 and started wearing a flat knit compression garment the same year. Her interests were doing sports and socializing with friends and family. Her roles as a mother and wife were important to her. She had a supportive husband. Mary went back to do what was expected from her as a wife, mother and friend after her cancer treatments and she was actively involved in activities at home and taking care of her children. During the analysis there were the following themes: ‘I can do everything and more’, ‘Consider it maintenance’, ‘Security and protection’, and ‘People’s reaction’ towards the garment.

#### **4.4.1 Theme 1: I can do everything and more**

Mary wore the garment because it helped her to do her activities during the day and provided the security to fulfil her roles.

“So, when I do my usual routine during the day I'm driving, praying, shopping, I wear the garment and I find the compression helps with the circulation ... I struggle with circulation in my right arm. Um, so I get this feeling of heaviness and on top of my hand, a bit of swelling. Um, so what happens is when I lie down as well, I sometimes get pins and needles in my arm and my hand. So, I feel I should wear my garment for at least 24 hours, I know I'm not supposed to sleep with it, but I actually find that sleeping with it, it actually gives me comfort.”

The reductions in impairments helped her to do what she wanted to do.

“I do a lot of things in the day that I've done before, you know, I'm just careful, obviously I don't want to injure my right arm when I am doing boot camp ... Um, but when I do exercise, I really exercise with it though, because when I was exercising, I felt at peace.”

She did not experience physical discomfort when she wore the garment.

“...it's not even uncomfortable. It's not even hot. It doesn't make you hot. The fabric is actually very nice ... it's pleasant. It's pleasurable to me.”

#### **4.4.2 Theme 2: Consider it maintenance**

Mary allowed her symptoms and lifestyle to determine her wearing schedule. Rather than wearing the garment all the time she wore it when her arm was painful or felt uncomfortable. To her it was a maintenance strategy that she controlled.

“I don't wear it permanently. It's just when I feel the heaviness or I feel the pins and needles ... I don't wear my garment if I don't need to ... I'm not sure what the rule is ... with my busy lifestyle, I'm only wearing it if I have some form of pain or swelling. I could possibly wear it more often ... I consider the garment now just as maintenance. So, um, it gives me a feeling of security because I know once I wear it, my arm will feel better. So, I have that comfort. Um, and I only have to wear for a short period of time to feel the difference.”

This way she controlled the situation and maintained a good relationship with the garment. She felt that she would have resisted wearing her garment if she was forced to wear it every day.

“I think any of us, if we are told, wear something all the time, which we will have an issue of it, but if you had the option to wear it, when you want to, it makes it a more applicable [sic] thing to do.”

At the same time, she recognized the garment as important and saw it as part of her life.

#### **4.4.3 Theme 3: “Security and protection”**

Mary felt lucky and privileged that she has access to this kind of treatment. She compared it to vitamins and other lifestyle choices that people make. She wore a compression garment for her wellbeing. The garment provided her with security, and she felt it protected her.

“... everyone does something to their lifestyle, you know, whether it's taking vitamin or seeing a homeopath, everyone does. So, I just think this is something that I do ... I know really, it's going to help me so emotionally, I know I just need to be good and wear my sleeve and for a short period, and I can take it off just before I can move into my cooking or doing dishes or whatever. And it gives me a security that gives me comfort ... It's really one of the best things ... I could have purchased.”

She saw the garment as a medical intervention strategy like aspirin for headache, a self-medication you choose when the symptoms prod you rather than chronic medication taken daily.

“... like a treatment, you know, mm-hmm, if I feel my arm is sore, if it's been hot, when I went walking for an hour and my arm feels heavy, or I carry shopping bags that I shouldn't do in my right arm, you know, and I should have taken a trolley and I feel my arm, it's got a bit of a pain, or if I have pins and needles in my hands only then I wear it ... I just love medicating myself, <laugh> it's [wearing the compression garment] something you can do for yourself at home.”

Mary's positive outlook on compression garments might be due to her experience as a child. Her mother had breast cancer and she can remember how her mom suffered with a swollen and heavy arm, because she did not have access to a compression garment.

“I don't feel sad. I actually feel very lucky. You know, my mom had breast cancer, she had breast cancer and I was in standard five, which was the last standard of primary school. And I remember her having her arms always felt heavy. And I remember her quietly struggling and I always think how lucky I am to have all these resources ... and so much information out there. We really live in a period of information, there's so much positive information. So, I consider myself very lucky to have access to this kind of treatment.”

#### **4.4.4 Theme 4: People's reaction to the garment**

The attention that was drawn by the compression garment made Mary uncomfortable. While not shy about the garment, she was uncomfortable with the conversations it attracted. She explained that she did not go into explanations about cancer and lymphoedema, but rather just mentioned that it improved circulation. She would not ignore questions, but she would rather give a generic answer that would not cause further curiosity and move the conversation to her illness.

“I'm not shy to wear short sleeves with my garment ... I feel like I have to explain myself ... If people do notice it, I just tell them it's for circulation. And a lot of people understand that they don't necessarily know it's because of breast cancer and a breast operation or removal of the lymph glands. But when you tell people it's for circulation they do understand, you know, because if you go into a Dischem, for example, you'll find an aisle, that has socks, you know, um, thrombosis socks, uh, socks for circulation, uh, even at the sports shops, you know, they sell compression garments ... So, I think people probably think I'm wearing something from Mr Price sports <laugh>, which some sports people do wear anyway.”

She chose a garment which was closer to her skin colour to make it less noticeable and not drawing attention towards the garment.

“I think I chose a flesh colour so that people don't notice ... I think if I chose a snakeskin, I think people would've been a bit shocked, but the flesh colour is really a good option to take.”

#### **4.4.5 Conclusion**

Mary was thankful for having something that assisted her to manage the lymphoedema while still doing everything she wanted too. The compression garment gave her confidence to exercise and provided her with security to fulfil her roles. It improved her physical discomfort and decreased the swelling. And she felt she had choices and control concerning type of garment and her wearing schedule.

#### **4.5 Participant 4: Abby**

Abby started wearing compression garments in 2015. She was self-employed at a company that sells compression garments with a wide range of designs. She acknowledged that this job might colour her perspective of compression garments. “I think I'm unique in this because I've made lymphoedema my work and my world ... I've

turned this into a part of my life.” Abby’s narrative was particularly rich and led to five emerging themes. They were, ‘Controlling the narrative’, ‘Finding the right garment’, ‘Service provider, my cheerleader’, ‘Corporate culture’ and ‘A journey’.

#### **4.5.1 Theme 1: “Controlling the narrative”**

Abby started by saying, “I have no issues with my compression garment anymore”. As her narrative unfolds, we realise the importance of this seemingly simple sentence and especially the use of “anymore” at the end. Through controlling the narrative and taking back her right to choose, she moved from a place of frustration and physical discomfort to not only accepting the garment but seeing it as a fun accessory that can add spice to her day, while performing its inherent role of managing lymphoedema.

“I finally found a happy place and I don't even think about my garment anymore ... obviously part of the reason I'm okay is because I've also found something that I feel like I've been able to blend with my lifestyle, which was really important ... You wear it all day. You don't think two seconds about it. You can go about your day lifting what you need to lift or doing what you need to do ... Like your life goes on and I think that's really important ... they [compression garments] need to just blend into the background of your life.”

Getting to this “happy place” point constituted a seven-year journey. She spent time searching for garments that she was comfortable with both in terms of how it physically felt on her body and in terms of how she felt emotionally about wearing it. Today she is content with wearing compression garments, even somewhat excited by it. Physically, the garment assisted her in her activities and thus life roles: “I just go do what needs to be done”. Socially it had become, if not a fashion accessory, at least a conversation starter that she enjoyed.

“... it is kind of a bolder pattern [the garments she wears]. So, you are sort of making a statement. It's kind of this weird, ironic, paradoxical relationship with

those sleeves because in some respects you are calling attention to it, but you're controlling the narrative. If that makes sense. Um, when I first started wearing the sleeves, I was very conscious of them, but because it was something I had chosen, I had chosen the pattern. I was sort of prepared for the narrative ... And I'll sometimes get people come up and say, I thought it was a tattoo and we'll have a little quick conversation around tattoo and like, you know, and then I move on from it. I enjoyed going public with the garment, you know, you picked your pattern, you picked it, <laugh> you knew exactly what statement you were about to make <laugh> so it wasn't something that I was afraid of. I was excited about it in some respects, because like, yeah, I had just combed through a hundred different styles to pick the two that I could afford to like go out with. So, I was actually kind of excited to see people's reactions to it. And, um, for me it was fun. It was fun wearing them out and getting people to kind of be like, what's that? ... I've been so grateful for those sleeves because I feel, I felt empowered by the journey. And I felt like that goes into owning the narrative, you know, and being able to control the narrative."

Abby emphasised the importance of choice, a choice between different garments since not every person likes the same thing. But also, a choice between the garments in your cupboard like you would have a choice between shoes: sport shoes for the gym and heels for the formal dinner.

"I think your choice of your sleeve, when you can choose it, you do a mental process that makes you ready to go out and show it. Versus like, if it's just handed to you, you're kind of like, "Can I stuff it in the back drawer and never be seen with it again?"

"I choose. So, if I'm camping, I'll wear the flat knit because it's a thicker, you know, it's not gonna snag. I just wear the appropriate garment for the setting ... you need to have a range of options because there are certain moments where you're doing



something that you need something different ... I absolutely am not, I will not go to a meeting wearing a flat knit garment because it looks ugly and it asks questions.”

#### **4.5.2 Theme 2: “Finding the right garment”**

Initially Abby was given a garment and told to wear it. Being almost forced to wear the garment rather than being a partner in the process caused her to resist. Physically she described that garment as follows:

“Um, poor, poor fit. I mean, I honest to God, I wish that orthotists would stop prescribing the one with the mitten in the hand because it's just the worst garment ever, ever, ever, ever ... It hurts. Um, it hurts at the, it hurts at the crease, so that was kind of a big thing. Um, and then also the inconvenience around trying to like for that particular garment, um, learn how to like wash hands ... Like you've got this whole new lifestyle of like even clothing choices, like you're having to now schedule your wardrobe around how you can wear your garments depending on what's been prescribed to you ... those things were inconveniences that I think in some respects weren't necessary. Um, and I think then there's just the practicalities of temperature and the roughness on the skin and like the discomfort of the garment was huge ... the pain ... some of these garments will inflict was, was crazy ... It was so much more uncomfortable, so then you're constantly fidgeting with it ... and trying to fight to try to get into a comfortable position. It was never something I could forget about.”

Emotionally the garments caused negativity.

“My relationship garment-specific was probably bad with those early ones ... here was anger and resentment, like having to throw away clothes that I really liked. I was like, I'll never get into this again. Because they [ the clothes] were tight little sleeves and that was just never gonna work. Um, and anger and resentment at,

um, paying a lot of money for something that was now hurting me and like feeling frustrated, and a bit hopeless.”

As her narrative shows, these garments never became part of life. They were uncomfortable and a constant reminder, an irritation. Whereas when she found garments that were comfortable and where she could choose the ones aesthetically pleasing to her, it became part of her life.

“Finding the right garment was a hundred percent, like finding the [mention company selling garments with different design patterns] changed my life. I went from feeling like this was something being done to me to something that I was now in power of. Like I had a choice in what I wanted. I had a choice and, and I didn't have to be dictated to anymore. I'm a well-educated person who researches things to death and I think those early days feeling like my decisions were being taken away from me, I was just being told, like pay this money, wear this, um, and that when those weren't working for me were demoralizing and defeating ... So yeah, finding [brandname] and then finally being like, I can actually take control over my journey. There's something I can do for myself that I'm happy with ... I've got a solution that I'm happy to live with was a big thing ... it doesn't hurt, which is a huge advantage ... now, because my arm's a little bit small, smaller [I] can now get back into most of my clothes, which is great.”

#### **4.5.3 Theme 3: Service provider, my cheerleader**

Abby felt that health care service providers have a role to facilitate the client's journey to finding the right garment, which they were not always fulfilling. Service providers should be guiding partners. They should use their knowledge and experience to empower the client to make choices that address their physical and emotional needs. The adage of being on tap rather than on top comes to mind. Sit with me, listen to me, ask me. See me as a person, not a case.

“There is a disconnect ... the thing that resonates across the board with many of us [compression garment users] ... like so frustrated at feeling not listened to, like when I say my garment hurts me ... Like when I say I'm embarrassed to wear this, I don't want to hear back the medical reasons as to why. I'm well acquainted with the medical reasons as to why, but I have to process what it is for me to live with this condition. Not for me to treat this condition.”

She realised that patients sometimes have a lack of knowledge, or are unsure, even unwilling to make decisions. But she advocated strongly for a person-centred approach where the user is empowered with knowledge and supported to a place where they are confident and willing to make the decision.

“We've got a problem with patient passivity and I think even if a patient is on the surface shutdown in that process, having a doctor, encouraging them to engage is gonna have a longer-term benefit on the patient's ownership of their process, [rather] than having something thrust upon them ... starting to embrace patient advisement as more of a model of approach towards medical care, you know, that empowering patients with information so that they can make informed decisions. Um, and standing there as a support network and an encourager, like a cheerleader behind the scenes, you know, um, helping patients to achieve their milestones and their goals ... if every medical provider could kind of start to make that mental shift, it would, I think the, the landscape of medical care across conditions would be so much more vastly improved.”

#### **4.5.4 Theme 4: Corporate culture**

While Abby herself did not have a problem with wearing the garment in public, she did talk about the impression it can create in the workplace. She felt that being singled out as different, sick, or disabled can be a disadvantage especially in the work and corporate environment. Her opinion was that every person should have the choice whether they want to make others aware of the lymphoedema through wearing a garment or not, while

still having the health benefits of controlling oedema and pain through a compression garment.

“It is important to not overlook corporate culture ... the challenge, women re-entering the workplace post a significant challenge, like breast cancer. And especially if you are in more of a senior management to executive level ... you just hear these women kind of grappling with the recovery, you know, all aspects of the look and feel of recovery ... and I can easily see how, trying to re-establish yourself as ready to work ready ... do you feel comfortable in your corporate culture, or do you feel like you're viewed as damaged goods kind of thing, you know, and is it impacting your business? Not just from like, can you still do your job, which is a big problem for many people, but also, do you feel like the perception of your lymphoedema is impacting your ability to get promotions, your ability to be perceived as, um, yeah, top of your game. And I think many of them are struggling with that, you know, and realizing that I'm not top of my game, I'm worried about being able to claw my way back to the top of my, my game. How do I do this with the stigma that now I constantly walk around with?”

“I'm hearing so many women talk about their struggles ... where lymphoedema is a disability for some people. And when you've got an employed individual, who's trying to justify why they should be back at work and not having a boss, kind of looking at them, going I need to replace this person because, clearly they're not gonna be able to hold this job for long. It's a big factor of how you frame it. So, walking in wearing a bandage into your office, not a great power ... Like if you're trying to re-establish yourself as I'm here in the office and I'm ready to like take hold of my life, wearing a big bandage into the office is exactly kind of the opposite message of what you're trying to send.”

The compression garment calls attention to itself. But Abby felt with aesthetically pleasing garments the wearer was empowered to decide whether to call it a fashion

statement or talk about her condition. An important choice in social and work environments.

“I can shrug it off to a fashion statement if I'm not wanting to go into great detail. If I'm feeling sensitive about my condition, I can kind of pass off those sleeves to a different conversation if I'm not ready to have the deeper conversation around cancer or lymphoedema. So, and that's important, you know, it's important how you engage with, um, public, it's important, how you're perceived in business.”

#### **4.5.5 Theme 5: “A journey”**

Abby described that getting used to wearing the compression garment was like a journey. She had to find a rhythm; a give and take. She could not allow the garment to take over her life. But at the same time, it must be part of her life.

“I think with any garment that's prescribed, there's going to be a level of that adaptation that needs to come even with your best fitting garment. When you first put a participant into it, there's going to be a degree of adaptation and discomfort. That needs to be overcome. And that takes a while to do. I don't think there's any way around that: the pressure, the, even, even in the best garment ever, just having suddenly having pressure on your arm versus not, you know, and then finding that rhythm and knowing how to kind of adapt and like what's gonna work for you, how you wear your clothes ... It's a journey. I'm, I'm trying to think where that transition would've occurred and it was probably, you know, probably took a good year. You know what I mean before I kind of, wasn't thinking about the sleeve when I walked outside the door ... so it is a bit of a process journey that doesn't happen overnight.”

“Um, yeah, it's a whole lifestyle, like rethink, you know, which you wouldn't think that it should be that intense, you know, it's just, but it does end up being, I think, I think many people kind of describe just an early awkwardness with trying to figure

out like, you know, how do you manage all these things? ... I've been able to kind of reconcile how that would fit with my lifestyle and to create a space in my lifestyle for it. And um, that, but that creating a space for my lymphoedema treatment in my lifestyle took me time.”

#### **4.5.6 Conclusion**

For Abby it was about being in control of her life rather than have a compression garment control her. It was about choice. Making peace with the compression garment was about finding suitable garments. They had to be physically comfortable while doing their job. They had to fit her lifestyle and they had to be aesthetically pleasing. She wanted, needed choice and control. The garment had to blend into her lifestyle while managing the oedema rather than taking over her life.

#### **4.6 Participant 5: Clare**

Clare was employed at a primary school as a house mom. She started wearing a flat knit garment in 2021 after she was diagnosed with a mild lymphoedema. Four themes emerged from Clare’s interview. They were ‘Building confidence’, ‘Yeah, it sucks’, ‘The unknown’, ‘Wearing it in public’.

##### **4.6.1 Theme 1: Building confidence**

Clare felt that the garment increased her confidence through its protection of her arm against swelling, pain and other adverse symptoms. She was confident that she could do what she needed to do and what was expected from her while wearing the compression garment. The compression garment gave her assurance to do things that she could do before her cancer diagnoses. Her participation in everyday life was assisted rather than hindered by the garment.

“I don't think it's, it's sort of affected any of my activities. I feel like I can still go ahead and do whatever I need to do ... I am more confident in picking up a

shopping bag when I'm wearing my sleeve than without my sleeve. So, I've become very selfconscious about what I do when I'm not wearing my sleeve. And I've just become conscious of everything that I do with my arm, um, but I do feel, if I'm wearing my sleeve, I feel more confident.”

“

And I think people feel shame. And like, I want to say, no, actually. But it's fine. It is what it is. Um, but I don't get embarrassed about it or anything like that. Okay. Um, but it's, I'm, it's different people's reaction is, you know, they, they feel for me almost about having to wear it and I just say, no, it's fine. You know?”

Physically her arm felt better overall when she wore the garment.

“... by putting on the sleeve, it almost felt, um, it's hard to explain and it felt like that pain was now contained. And it just felt better wearing it. I was feeling uncomfortable, and I couldn't tell why, but by putting on the sleeve actually, yeah, it just helped with the pain ... it's not the same pain every day. Um, it just this burning sensation, but by putting on the sleeve that actually did assist with, with that sort of pain.”

However, as theme 2 will further explore emotionally she did not always find wearing the garment easy. When the emotional effort of wearing the garment got too much, she would remove it despite symptomatic relief it gave her.

“I put it on and I thought today is not a good day. So, I took it off. And then yet the one morning my arm felt a bit ‘burny’ and a bit sore and I put it on and it was quite comfortable and I was glad I had it on and I wore it for most of the day ... I am aware that it is better to wear it and I'm fine to wear it. And then as I say, I had one day where I'm like, it's just, today is not a good day.”

#### 4.6.2 Theme 2: “Yeah, it sucks”

The realisation that wearing the garment was not something she could easily ignore took an emotional toll on Clare. The tightness and pressure meant that she remained physically aware of it. That physical discomfort translated into emotional despair.

“When I got it and we tried it on and I just realized like, yeah, I just, I was very disheartened in realizing how tight and uncomfortable it was ... really, really uncomfortable ... it's like they [other people] say shame and I like, I almost wanna say, yeah, it sucks. You know, I wanna almost like agree with them “.

“I hated wearing it.”

She wanted to rid herself of the discomfort but tried to hang on.

“I think just frustration, I sometimes get frustrated. Like I think, oh, I just want to take it off and I think, no, you can wear it a bit longer.”

Then there was the added realisation that this was not temporary. She will have to wear the garment and deal with the emotions it created for the rest of her life. She realised it would have to be integrated in her lifestyle. Contemplating that she will have to wear the garment for the rest of her life, and the practicalities that went with that, was not easy.

“And I think my biggest, I suppose, shock was when I said, well, how long do I have to wear it for? Because I thought maybe a month or whatever. And I think you and her said for life, and I was like, I didn't bargain on this. I didn't ask for this ... I felt very disheartened that I would probably have to wear this off and on always.”



#### **4.6.3 Theme 3: The unknown**

Clare started wearing her garment less than a year ago. It was and still is a big adaptation for her. She did not enjoy wearing the garment. She felt unsure about the purpose of wearing the garment. While a health care service provider did try to explain, the explanation was either not enough or not done in a way that helped her understand.

“I think when I was first told that I should consider wearing it, um, I don't think I had any idea of what, what to expect ... I didn't really understand what lymphoedema was. Um, so I think possibly if I'd been more educated in that, maybe even shown visuals of this is what lymphoedema is, to realize actually how serious it is. Um, and also, um, I know that the physiotherapist, she was really good in trying to expand, but thinking about it now, um, I think just, um, being more educated and why it's important to wear it.”

She was not wearing it daily and this also created a feeling of worry because she was unsure of what can happen if not wearing it daily and what the consequences would be in future.

“Like the consequences are, is that quite serious. Or can I go have a day or two in between that I don't wear it or, yeah. So, I think, yeah, I just, I, I really don't enjoy wearing it. I just find it very uncomfortable ... I, I suppose just if I knew more, I would then maybe be more, um, aware of how important it is to wear.”

#### **4.6.4 Theme 4: Wearing it in public**

While frustrated with wearing the garment due to its physical discomfort she was not bothered about what others think.

“I am aware of, of people noticing it, but I am, I, I'm not like, oh my gosh, I can't wear it because I don't want people to see. You know, I just. If I need to wear it, I'll wear it ... I don't get embarrassed about it or anything like that.”

What did bother her was when it evoked sympathy which she did not want. The choice not to wear it was not driven by being worried that others would notice the garment, but because she was physically more comfortable without it.

“I think it's more discomfort than anything else. It's not necessarily the look, it's just the, more the comfort. So just like sitting with a friend and putting your arms and drinking tea or whatever ... if you can meet and it's gonna be a social place and time, it's more the discomfort than the actual look. “

#### **4.6.5 Conclusion**

To Clare the journey of receiving a compression garment was disheartening. She was surprised that she will most probably wear the garment for the rest of her life. She preferred not to wear the sleeve when she went out with friends but wore it at work and home and did not mind questions about it. The compression garment gave her confidence and she felt secure with it. The benefit of the compression garment motivated her to push through the physical discomfort she experienced when she wore the compression garment.

#### **4.7 Overall conclusion**

During the interviews participants raised the struggles they experience with the compression garments. All of them except one felt the garment drew attention, which was often unwanted, and felt self-conscious when they wore it in public. They experienced feelings of frustration and feelings of security during the processes of receiving and wearing the garment. The participants preferred to decide their wearing schedule and that gave them control. They felt confident with the compression garment on and felt it gave them the ability to participate in their life roles, but also that it made them stand out and look different.

## Chapter 5

### 5. Cross-case analysis: Compression garments; a double edged sword

#### 5.1 Introduction

Four themes “Controlling the narrative”, “Braving the public”, “A double edged sword” and “Influence on mental health” emerged from the cross-case analysis. Themes one and three were identified through subsumption (Smith, 2009) where a theme that emerged in one participant’s analysis became the cross-case theme that pulled together related themes or codes from other participants’ narratives. Abstraction (Smith, 2009) led to theme two where similar themes/codes from the participants were placed together under a different name. Theme four emerged through polarization (Smith, 2009) as the themes/codes that were brought together here are opposing to an extent. The cross-case themes are presented as per the example of Van der Merwe and Habron, (2018) in table 5.1 indicating the themes from each participant and a supporting quote for each cross-case theme, and then further explored in the text.

**Table 5.1 Cross-case themes with examples from individual participant themes and narratives**

<b>Cross cutting theme</b>	<b>Anne Theme s</b>	<b>Quote</b>	<b>Sophie themes</b>	<b>Quote</b>	<b>Mary themes</b>	<b>Quote</b>	<b>Abby themes</b>	<b>Quote</b>	<b>Clare themes</b>	<b>Quote</b>
<b>Controlling the narrative</b>	A Nuisance	“...they don't always see me wear it. But when they see me wear it then they know, okay, your arm is not feeling right ... and then they	Schedule	“I wear it in the morning to the afternoon ... I still check my time, like when it gets to five or six... I'll take it off...”	People's reaction to the garment and Consider it maintenance	“But when you tell people it's for circulation, they do understand ... people probably think I'm wearing something from Mr Price sports <laugh>, which some sports people do wear anyway.” “...	“Controlling the narrative”	“I've been so grateful for those sleeves because I feel, I felt empowered by the journey. And I felt like that, like that goes into owning the narrative, you know, and being able to control the narrative.”	Building confidence	“I put it on, and I thought today is not a good day. So, I took it off.”  “I think people feel shame. And like, I want to say, no, actually. But it's fine. It is what it is. Um, but I don't get

		know they must help.”				if we are told, wear something all the time ... we will have an issue of it, but if you had the option to wear it, when you want to, it makes it a more applicable (sic) thing to do.”				embarrasse d about it or anything like that.”
<b>Braving the public</b>	“That is not dressy”	“It’s just that I won’t wear that outside because it’s ...	One of the team and Unwant ed	“I don’t want them (colleague s) to think, oh, she can’t do this”	People’ s reactio n to the garmen t	“I feel like I have to explain myself ... If people do notice it, I just tell them	Corporate Culture	“It’s a big factor of how you frame it. So, walking in wearing a bandage into your office, not	Wearing in public	“I am aware of people noticing it, but I’m not like, oh my gosh, I can’t wear it

you're a woman. That's not dressy."	attention	"I don't mind talking about it. I just don't want anyone to feel sorry for me."	it's for circulation"	a great power ... Like if you're trying to re-establish yourself as I'm here in the office and I'm ready to like take hold of my life, wearing a big bandage into the office is exactly kind of the opposite message of what you're trying to send."	because I don't want people to see ... If I need to wear it, I'll wear it ... I don't get embarrass- ed about it or anything like that."
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<b>A</b> <b>double</b> <b>edged</b> <b>sword</b>	A nuisanc e	"It's helping but it's not that	"A double- edged sword."	"it's a bit of a double- edged sword for	"I can do everythi	"So, when I do my usual routine during the	Finding the right garment	"It doesn't hurt... reduced pain which is a huge	Building confidence and "Yeah, it sucks"	"I don't think it's, it's sort of affected any of my
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		comfortable.”		me ... it makes me feel vulnerable but also confident if that makes sense.”	ng and more”	day I'm driving, praying, shopping, I wear the garment and I find the compression helps with the circulation.”		advantage. I can't go without a garment, or I get like, pain on my arm. Um, and obviously I then now, coz my arms a little bit small, smaller, [I] can now get back into most of my clothes, which is great.		activities. I feel like I can still go ahead and do whatever I need to do ...”  But also I was very disheartened realizing how tight and uncomfortable it was “
<b>Influence on mental health</b>	“Frustration”	“I won't like get emotional in the sense I will cry or	Security	“Maybe it's giving me a full security when I wear it ... I	“Security and Protection”	“It's really one of the best things ... I could have purchased.”	A journey	“I think with any garment that's prescribed, there's going to be a level of	“Yeah, it sucks	“I hated wearing it ... frustration, I sometimes get

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ble it was.”



## **5.2 Theme 1: Controlling the narrative**

The importance of being in control about decisions surrounding the compression garment such as how long and when to wear it, what type of garment to wear and choices on garment colour and design were mentioned to a greater or lesser extent by all participants. Participants developed wearing schedules that fitted their lifestyles and emotional needs. Freedom of choice seems to aid adherence to wearing the garment. When emotions were ebbing and they could not face wearing the garment, they chose not to wear it: “I actually just, I put it on, and I thought today is not a good day. So, I took it off.” (Clare)

However, controlling the narrative went further than physical choices around the compression garment. It encompassed verbal and nonverbal messages. Participants wanted to be in control of the discussions they have around the compression garment. In Abby’s words, “I’ve been so grateful for those sleeves [the ones that provided her with a choice of colours and designs] because I feel, I felt empowered by the journey. And I felt like that, like that goes into owning the narrative, you know, and being able to control the narrative.” Colours and designs drew the focus away from the medical aspect of wearing the garment to discussions about tattoos, circulation, and sports. Sometimes the act of wearing the garment became the narrative that gave a message like, I need more help, without having to say it.

## **5.3 Theme 2: Braving the public**

All the participants were conscious about wearing the compression garment in public. The conversation about wearing the garment in public then also ranged widely from some actively hiding or not wearing it to Abby who chose to make a statement with it. Clare and Abby did not mind others seeing the garment, but for different reasons. Anne, Sophie and Mary were less comfortable with others noticing the garment. Three aspects of the garment being visible in public that emerged was the conversations that could be started by that, how it can lead to unwanted and harmful perceptions at work, and that it detracts from being dressed up.

**The conversations started by the garment:** Anne, Sophie, Mary, and Abby talked about this aspect. For Anne, Sophie, and Mary it was rather unwanted. They did not like being stared at or being approached by strangers who ask about the garment. Therefore, they chose to hide or not wear the garment. They especially did not want the conversation to move towards breast cancer and having people feeling sorry for them, or seeing them as different, on that account.

When they did wear a garment, they chose one, like what Abby did, that could influence the narrative in a manner they could control. The conversation will then be about circulation or the design on the sleeve. They chose to steer conversations in those directions rather than to explain about lymphoedema and breast cancer. “I just tell them it's for circulation. And a lot of people understand that. They don't necessarily know it's because of breast cancer and a breast operation or removal of the lymph glands” (Mary).

Realising that one cannot get away from the garment generating attention from strangers, Abby chose the option of a highly visible garment that is almost guaranteed to be noticed. But the garment itself becomes the topic of conversation, rather than the reason for wearing it. In this way she is in control. “So, you are sort of making a statement ... you are calling attention to it, but you're controlling the narrative ... I had chosen the pattern...I was sort of prepared for the narrative ... and we'll have a little quick conversation around tattoo ... and then I move on from it.”

In this way they curbed unwanted sympathy and conversations that are inherently private such as about their health.

**Unwanted and harmful perceptions at work:** Sophie and Abby felt that wearing a compression garment at work can imply that one is less able and might need special considerations. Abby especially explored the unspoken corporate culture of needing to perform and needing to be seen as ‘on top of your game’ as she called it, to be competitive. She felt wearing a type of compression garment that can detract from that image might be damaging to a career. “Like if you're trying to re-establish yourself as I'm here in the office and I'm ready to like take hold of my life, wearing a

big bandage into the office is exactly kind of the opposite message of what you're trying to send."

**It detracts from being dressed up:** Anne was unwilling to be seen with the garment because it did not fit her image of a well-dressed woman.

#### **5.4 Theme 3: A double edged sword**

All the participants felt their compression garments increased their ability to participate in daily activities and life roles through decreasing the symptoms caused by lymphoedema and controlling the swelling. To Sophie and Mary, the compression garment gave them the ability to exercise with confidence. While they all indicated these benefits of the compression garment, they also saw it as bothersome. It worked and did what it was supposed to do, but they still did not like this "thing".

The ability they had to fulfil their life roles with confidence made them not want to go without it and gave them reason to wear it. But did not take away the fact that it was annoying to them, "...it's a bit of a, a double-edged sword for me ... it makes me feel vulnerable, but also confident, if that makes sense." (Sophie). The vulnerability was related to the donning and doffing process, the constant awareness of the garment, the discomfort it causes, and not wanting to be seen as different or talking to strangers about their health.

An added frustration for participants and one that was part of the annoyance caused by the compression garment was that it influenced their choice of clothes. They were somewhat limited in choice of clothing either because they wanted garments that could hide the compression garment or because tight sleeves might not fit over the compression garment.

#### **5.5 Theme 4: Influence on mental health**

This theme showed opposing opinions with some describing negative emotions like frustration and irritation. Other experienced security and confidence. And finally, there was the opinion that it takes time to get used to the compression garment.

**Frustration:** Negative emotions like frustration and even depression came out strongly in the narrative of Anne. But it was also seen in other narratives, for instance that of Clare who wanted to agree with people who sympathise with her that having to wear the garment actually ‘sucked’. Abby also spoke of initial anger and resentment.

**Security and comfort:** On the other hand, the garment provided comfort against irritating symptoms and the security of knowing they can use their arm freely without fear of causing harm to it. Sophie explained that the difference is amazing between having the compression garment and wearing it and to be without it. “And it gives me a security that gives me comfort ... It's really one of the best things ... I could have purchased.” (Mary)

**A journey:** There was also agreement between participants that one does not put on a compression garment, even the best fitting one, and become immediately used to it. It requires adaptation, getting used to. And getting used to it takes time, is a journey as described by Abby. Being unsure and not informed about the condition of lymphoedema and the role and use of a compression garment in conjunction with a feeling of not being listened to and not having their feelings acknowledged by service providers made the journey more difficult. They struggled to accept the fact that they would have to wear the compression garment for the rest of their lives.

## Chapter 6

### 6. Discussion

The impairment modifications provided by the compression garment that current study participants identified concurred with those identified by Bahtiyarca and colleagues (2019). Also, like Bahtiyarca et al's (2019) findings, participants generally agreed that they could do everything they did before their diagnosis. Miller (2018) on the other hand found that women who wear compression garments felt limited in their daily activities. In the study done by Bahtiyarca et al (2019), all participants had surgery as the only treatment for breast cancer and developed lymphoedema in the first year after surgery. Lymphoedema was diagnosed and they started with treatment soon after diagnosis. These participants could get their swelling under control quickly and this might be the reason that their activities were not affected, and they could do everything they did before their diagnosis. The study Miller (2018) did was based on a specific type of flat knitted compression garment and can therefore be the reason behind their results. Participants felt that this type of garment limited their activities. According to Fong et al (2020), the wearing of compression garments supported physical activities and exercise. This is another literature finding that current findings agreed with.

Being in control is a need most humans have (Greenaway, Cruwys, Haslam & Jetten, 2016). We want to decide what to do, how we want to do it, and what to talk about to whom. Thus, it is not strange that choice and control caused better adherence to compression garment wearing and improved mental acceptance of the garment. This need for control should be respected and utilized by service providers (Kim, Choe, Cho, Park & Lee, 2022; Muñoz-Alcaraz, Pérula-de-Torres, Serrano-Merino, Jiménez-Vílchez, Olmo-Carmona, Muñoz-García, Bartolomé-Moreno, Oliván-Blázquez & Magallón-Botaya, 2020). When people are forced to do something, push back often results. Guidance, explanations, and choice empower people. Service providers can listen and provide a safe environment where feelings and experiences as well as the health condition can be explored, and appropriate solutions can be determined. This includes developing an understanding of their

user's social environment, where they fit into and what their roles are in society (Muñoz-Alcaraz et al., 2020; Kim, 2022). How the compression garment treatment can increase user confidence should be taken into consideration, rather than just supplying a garment and training about the wearing and maintenance schedule. Users can then make an informed decision on how and when to wear the garment, being fully aware of the consequences of their decisions.

Participants also wanted to control the narrative around the compression garment. Wearing something unusual with a seemingly medical connotation can lead to a plethora of unwanted responses. Inquisitive questions about health and medical care, staring, unwanted sympathy, avoidance and stigma are but a few (Fu, Ridner, Hu, Stewart, Cormier & Armer, 2012). It differentiates the wearer from others. Causing social anxiety (Río-González, Molina-Rueda, Palacios-Ceña & Alguacil-Diego, 2018; Kavola & Suominen, 2018) and decreasing their confidence Taghian et al (2014). The big influence peoples' opinions can have, has been shown by the fact that some would choose not to wear something that will improve function, take away pain, and control swelling rather than to be seen with it.

While already unwanted in social circumstances, negative reactions from others can be very harmful in the work environment. The compression garment and what it stands for might be perceived as a 'weak spot'. This in turn can harm employment and promotion opportunities (Bonaccio, Connelly, Gellatly, Jetha & Martin Ginis, 2020).

Wearing something fun, different, or even shocking leads to different narratives. Participants indicated that if they could not hide the compression garment, they want to steer the conversation to topics they are willing to talk about. However, this control might be about more than steering the conversation. It might be about facilitating different or no emotional responses. A short chat about circulation is soon forgotten, whereas an explanation of lymphoedema and breast cancer might evoke pity.

The above connects to compression garments being seen as a double edged sword. While they do what they were supposed to do regarding managing impairments and

through that decreasing activity limitations, the social reaction to them might lead to them not being worn. In addition to the social reaction, there are also the constant irritating reminders (like discomfort, and heat), of being dependent on a lifelong intervention (Backler, Beck & Poage, 2020).

## **Chapter 7**

### **7.1 Conclusion**

In most instances the garment did little to hamper participation in life roles. Rather the opposite was true, that the garment provided comfort and security. The garments gave relief on an impairment level and with that supported activities and participation. However, accepting the compression garment as part of their lives for the rest of their lives was difficult. Emotions like anger, shock, irritation, and frustration were described. These emotions were counteracted by controlling wearing schedules, garment type, colour, and design. The compression garment needed to fit the lifestyle of the users and, in a way, become part of them rather than controlling them. Participants were often not comfortable to appear in public with their compression garments because of the negative attention and emotions it created.

### **7.2 Limitations**

Abby had been wearing a compression garment for 7 years and struggled to recall some of her experiences when she first started wearing the compression garment. Participants decided when to wear their compression garments and could not recall certain experiences because they had not worn the compression garment during those activities. Interviews were not face to face and it was not possible to see and interpret the body language of the participants and I could also not witness them in their own environment. Even though I did reflexion throughout my study and the fact that the study is not about my service or the quality of the compression garments that the participants are wearing, but about the experiences of the compression garment in their participation of life roles. I am aware that me being the treating therapist could have created bias and therefore I acknowledge it as a limitation.

### **7.3 Recommendations**

It is recommended that healthcare practitioners follow a user-centred approach when providing compression garments. This should include developing an understanding



of the emotional wellbeing, social circumstances, and life roles of the user. Take the time to listen to users' concerns and feelings about the compression garment. Know that the garment will influence the mental, physical, and psychosocial wellbeing of each user differently. Be informed about the different compression garment options available to users, the advantages, and disadvantages of each, how their different characteristics will fit or not fit into the user's lifestyle. Provide users with information on the different options and support them to make a choice.

It is recommended that compression garment users make sure they understand the function and benefits of the compression garment, and how it can be integrated into their daily routine. Demand choices. Decide on a print and colour that will blend in with your lifestyle. Get a second opinion. Have more than one garment so that you can choose to wear the one most suited to the activity you will be doing.

It is recommended that compression garment manufacturers expand the range of garments they manufacture to include garments for different purposes and in a range of different colours and designs.

Further research can be done on the exact wearing time necessary to maintain control of lymphoedema to have the approach more patient centred and can work with every patient's circumstances, and the psychosocial influences of compression garments in people with breast cancer lymphoedema.

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## 9. Appendices

### Appendix A: Population spreadsheet

Participant	Age	Marital status	Employment status	Type of garment	Wearing garment since

## Appendix B: Participant Consent Form

# PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

Title of Research Project:	
The role of compression garments in the participation of life roles of women with breast cancer-related lymphoedema; a qualitative exploration.	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Mrs Marzanne Altin	Ethics reference number:
<b>Full postal address:</b> Marzanne J v Rensburg Orthotics & Prosthetics, Room 403, Sea Point Medical Centre, 11 Kloof Road, Sea Point, Cape Town, 8005, Western Cape, South Africa	PI Contact number: 0723865952

I would like to invite you to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask myself, Marzanne, any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary**, and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

**The Health Research Ethics Committee at Stellenbosch University has approved this study. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research**

**Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).**

What is this research study all about?

- I am doing the study to investigate the experiences that women with breast cancer-related lymphoedema have regarding the role of their compression garments in their life. It is about how the garment affects you in your functioning daily.
- Five to six women will be asked to participate in the study.
- I will ask you about your experiences during individual virtual interviews. We can use Teams, Zoom, Skype or WhatsApp depending on your preference.
- I would like to do two interviews with you. The first one will be 60 – 90 minutes long and the second one four to six weeks later will be 30 to 45 minutes long.
- The interviews will be scheduled at a time that suits you.
- During the first interview I will ask general information like your age, employment status, marital status, the type of garment that you wear and the time that you have been wearing your garment. I will also ask questions to find out more about your experiences and your abilities to do things that are important to you such as parenting, doing your job, doing chores, being a wife, and social activities while wearing your garment. I will be interested in your physical as well as emotional experience. I would also like to know if you feel there are advantages to wearing the garments, if your cultural background affects you wearing a compression garment and if your religion affects you wearing a garment.
- Between one and two months after the first interview we will have a follow-up interview where you can share any experiences that we did not discuss in the first interview and where I might ask for further explanation of things said in the first interview.
- With your permission the interviews will be audio recorded. The reason for the recording is that I can have a record of your exact words. Only I will have access to the recordings. If you are willing to be interviewed but do not want to be recorded, you can let me know and I will not record the interviews.
- After I have analysed the information, I will send a copy of it to you via email and ask you to comment on whether it reflects your experiences truthfully.
- The interpreter will sign a confidentiality form. Once all the data are analysed, I will write up the report. The interpreter will only be present if the participant is isiXhosa speaking. If the interview is in Afrikaans and English, I will be the only one in the room on my side during the interview.

Why do I invite you to participate?

I invite you to participate because I feel you can add richness to my data and share your experiences to help create a better understanding of the role of compression garments in your daily life. Women older than 18, who received a compression garment from my practice for breast cancer-related lymphoedema, live in Cape Town, are fluent in Afrikaans and/or English and/or isiXhosa and have access to a virtual platform for the interviews will be invited to participate in the study.

What will your responsibilities be?

Your responsibility will be to answer the questions as truthfully as you can. To ensure confidentiality, you should ensure that you are in a quiet, private space when participating in the interviews. On my side I will be alone in a private room except during isiXhosa interviews when an interpreter will join me. You will be requested to participate in two interviews, and you will be asked for some feedback on the results which will be sent to you a month or two after the interviews. The interviews will last between 60 and 90 minutes and 30 and 45 minutes respectively. The feedback should not take more than an hour of your time. You can let me know as soon as you are uncomfortable with any questions, need a break from the interview, or want to stop the interview.

Will you benefit from taking part in this research?

Not directly no, but your experiences may benefit future patients. We might through the study be able to provide information on the general experiences of women receiving compression garment treatment for breast cancer-related lymphoedema to clinicians, which may have a positive impact on other women's experiences of the treatment. For you there may be emotional benefits from talking about and sharing your experiences.

Are there any risks involved in your taking part in this research?

- The sensitivity of the topic is acknowledged, and I know that some questions may elicit unexpected emotions. Should you feel you need emotional support you will have the option to have two sessions with a social worker or counsellor of your choice which will be paid for by me.

Stellenbosch University will provide comprehensive no-fault insurance and will pay for any medical costs that came about because participants took part in the research. The participant will not need to prove that the sponsor was at fault.

Will you be paid to take part in this study and are there any costs involved?

You will be compensated to take part in the study and your expenses will be reimbursed for each interview. You will not have to pay for anything if you do take part. The amount and method of payment to research participants should reflect the following two components:

- Compensation for data usage; R150 per participant per interview
- Gift for participation; R200 per participant (R100 per interview)

### **Who will have access to your medical records?**

I am the only one that will have access to your clinic records. No other medical records will be accessed. All information collected during the study will be treated as confidential and protected. Your identity will remain anonymous in the presentation of the findings.

### **Is there anything else that you should know or do?**

You can phone Marzanne Altin at 0723865952 if you have any further queries or encounter any problems.

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that your study doctor has not explained to you, or if you have a complaint.

You will receive a copy of this information and consent form for you to keep safe.

### **Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled (The experiences of women with breast cancer- related

lymphoedema regarding the role of compression garments in their participation in life roles.).

**I declare that:**

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been answered.
- I understand that taking part in this study is **voluntary**, and I have not been pressurised to take part.
- I may choose to leave the study at any time and nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.

Signed at (*place*) ..... on (*date*) .....  
2022

**Signature of participant    Signature of witness**

Declaration by investigator

I (*name*) ..... declare that:

- I explained the information in this document in a simple and clear manner to .....
- I encouraged him/her to ask questions and took enough time to answer them.
- I am satisfied that he/she completely understands all aspects of the research, as discussed above.
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.)

Signed at (*place*) ..... on (*date*) .....  
2022.

**Signature of investigator    Signature of witness**

Permission to have all anonymous data shared with journals:

Please carefully read the statements below (or have them read to you) and think about your choice. No matter what you decide, it will not affect whether you can be in the research study, or your routine health care.

When this study is finished, we would like to publish results of the study in journals. Most journals require us to share your anonymous data with them before they publish the results. Therefore, we would like to obtain your permission to have your anonymous data shared with journals.

Tick the Option you choose for data sharing with journals:

I agree to have my anonymous data shared with journals during publication of results of this study

☐

Signature\_\_\_\_\_

OR

I do not agree to have my anonymous data shared with journals during publication of results of this study

☐

Signature\_\_\_\_\_

## Appendix C: Interview schedule

Introduction	Thank you for taking the time to meet with me. As explained in our telephonic conversation I want to talk about your experiences with your compression garments. The interview will be 60-90 minutes. Are you still happy for me to record the interview? That is to make sure that I can access the data at any given time, and I don't want to lose important information. All the information will be kept confidential. Please remember that, if you feel uncomfortable about any question and prefer not to answer, you do not need to answer it. You may end the interview at any time.	
Biographical and demographic information	Review information from patient records	
Open ended questions	<p>Can you share your experiences and feelings about wearing a compression garment for lymphoedema?</p> <p>Please tell me what is difficult about wearing the compression garment?</p> <p>Can you tell me if you experience any emotional reactions when you need to wear your compression garments?</p> <p>Can you tell me about any advantages of wearing the compression garment?</p> <p>Can you tell me if and how your cultural background affects you wearing a compression garment?</p>	<p>Probes:</p> <p>Is it something that you experience daily?</p> <p>Is there something that makes it easier for you?</p> <p>What is it that makes you feel emotional?</p>



	<p>Can you tell me if and how your religion affects you wearing a compression garment?</p> <p>Can you tell me how the compression garment influences your doing the things that are expected from you?</p> <p>Can you tell me how the compression garment influences things you like doing (e.g., sport, leisure, social life, etc.)?</p> <p>Can you tell me how the compression garment influences your roles of <i>(add relevant ones here e.g., home maker, wife, mother, employee, friend, partner, etc.)</i>?</p> <p>Can you tell me about what it felt like the first time you had to go into public spaces wearing your compression garments?</p>	<p>Are the advantages worth the wearing of the compression garments?</p> <p>Do you experience the same feelings every time?</p> <p>How do you handle the influences the compression garments have on you?</p>
Concluding	<p>Thank you for your time to do this interview and share your experiences.</p> <p>Is there anything else that you want to share?</p> <p>Is it OK if I contact you for a follow-up interview where you will have the opportunity to share more information and I might ask further questions on what you have shared today?</p>	

## **Appendix D: HREC Ethics Approval Letter**

HREC ethics approval letter attached separately.