

DESIGN FOR EMPOWERMENT: SUPPORTING THE SELF-MANAGEMENT OF PEOPLE LIVING WITH A CHRONIC CONDITION (LYMPHOEDEMA) BY DESIGN

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Abstract

This thesis explores `empowerment` from the patient perspective and presents design guidelines to support the empowerment of people living with a chronic condition, lymphoedema.

Lymphoedema is a chronic condition that causes oedema/swelling of a part of body, commonly the arm(s) or the leg(s). It requires a daily management routine to avoid progression of the symptoms. People Living with Lymphoedema (PLWL) find continuously self-managing their condition challenging, and usually require comprehensive support. Patient empowerment is commonly set as an objective by healthcare organisations, to sustain their limited resources while maintaining patients' increased quality of life. Designed products and services have the potential to facilitate or inhibit this empowerment. This thesis investigates the research question `How might we design to support the empowerment of people living with lymphoedema?`.

An iterative design research process was followed. First, following a systematic literature review, qualitative studies on lymphoedema experience were synthesised with theoretical models on health behaviour. Then, primary studies including observations, interviews, cultural probes and a co-making workshop were conducted. Design probes were developed and utilised to explore the past (how it was), present (how it is) and future (how it might be) of self-management with study participants who had lymphoedema.

The results presented empowerment as a multidimensional journey. Provided support should be tailored to address the stage-specific needs of patients in their empowerment journey. Design guidelines are presented to facilitate empowerment by providing the right support at the right time for the individuals. This journey-based approach to patient empowerment can further contribute to the research on personalisation of adaptive products for health and wellbeing. Although this thesis focuses particularly on patients with lymphoedema, similarities with experiences of patients with other chronic conditions were recognised, opening up possibilities for future research on design for other life-changing conditions and journeys.

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Glossary and Abbreviations

Chronic Condition	<i>Medical health conditions that continue or recur for a long period.</i>
Self-Management	<i>Management of a health condition on a daily basis by the individual.</i>
Lymphoedema	<i>Progressive and chronic condition of oedema/swelling of a part of the body, commonly in arm(s) or leg(s). Caused by insufficiencies in the lymphatic system. (Section 2.1)</i>
PLWL	<i>PLWL (People Living with Lymphoedema) stands for people living with the chronic medical condition lymphoedema.</i>
Lymph(atic) Fluid	<i>Protein-rich and colourless fluid drained from human cells and tissues. Lymph fluid includes blood plasma, proteins, fats, nutrients, minerals, white blood cells, bacteria and virus.</i>
Lymphatic System	<i>Part of human immune and circulatory system. It works as a system of lymphatic vessels, nodes, tissues and organs to move lymphatic fluid back into the bloodstream. The lymphatic system contributes to the human immune system, maintenance of the fluid levels in the body and absorbance of the excessive fluids from tissues.</i>
Primary Lymphoedema	<i>Type of lymphoedema that is congenital and without an external/secondary cause.</i>
Secondary Lymphoedema	<i>Type of lymphoedema that is caused by damage to the lymphatic system due to injuries, traumas, poor venous functions, cardiac diseases, infections or, most commonly, cancer treatments.</i>
CDT	<i>CDT (Complete Decongestive Therapy) is a therapy, recognised as the standard lymphoedema treatment. CDT consists of two phases: intensive therapy and long-term self-management.</i>
Lymphoedema Therapist	<i>Healthcare professionals who have had specialist training in Complete Decongestive Therapy (CDT) for lymphoedema.</i>

Intensive Clinical Therapy for Lymphoedema	<i>A therapy carried out daily by a lymphedema therapist for around 2-4 weeks to reduce swelling, improve limb shape, tissue and skin condition. It includes MLLB, skin care, MLD, exercise and compression garment fitting. (Section 2.1.2)</i>
MLD	<i>MLD (Manual Lymphatic Drainage) is a gentle massage technique to increase activity in the lymphatic system and move fluid away. Usually applied by specialist lymphoedema professionals during the intensive therapy of the CDT.</i>
MLLB	<i>MLLB (Multi-Layer inelastic Lymphoedema Bandaging) is a bandaging technique to create graduated compression to the limb in order to restore shape, soften tissue and reduce skin changes. Usually applied by specialist lymphoedema professionals during intensive therapy of the CDT.</i>
Cornerstones of Lymphoedema Self-Management	<i>Four main strategies that are recognised in the self-management of lymphoedema: compression, skin care, exercise and massage. (Section 2.1.3)</i>
Compression Garments/ Sleeves/ Hosiery / Stockings	<i>One of the cornerstones of lymphoedema self-management is wearing compression garments. These are also called sleeves for arm garments and hosiery or stockings for leg garments. Compression garments help to reduce swelling, move the trapped lymph fluid through the vessels and help the muscles to pump this fluid.</i>
SLD	<i>SLD (Simple Lymphatic Drainage) is a gentle massage technique to help the flow of the lymphatic system. SLD is a simplified version of MLD that is advised to be undertaken daily by patients or their carer at home as a part of lymphoedema self-management.</i>
Fibrosis in Lymphoedema	<i>Hardening of skin and tissue resulting from a change in connective tissue fibres.</i>
Cellulitis	<i>An acute and spreading skin (dermis and subcutaneous tissue) infection (inflammation).</i>
LVA	<i>LVA (Lymphatic Venous Anastomosis) is a surgical operation for lymphoedema. It is a super-microsurgery that connects the</i>

	<i>damaged lymphatic vessels to a vein to allow lymph fluid drainage.</i>
BCRL	<i>BCRL (Breast Cancer Related Lymphoedema) is the type of lymphoedema arising secondary to breast cancer.</i>
HNL	<i>HNL (Head and Neck Lymphoedema) is a type of lymphoedema that is evident in the head and neck area of the body.</i>
GP	<i>GP (General Practitioner) is healthcare professional that treats common medical conditions and refer the patients to specialist services.</i>
NHS	<i>NHS (National Health Service) is the publicly funded healthcare system in the UK.</i>
NMC	<i>NMC (The Nursing and Midwifery Council) is the regulator for nursing and midwifery in the UK.</i>
HCD	<i>HCD (Human-Centred Design) is an iterative design process in which potential users and other stakeholders are central to the development of solutions. (Section 2.4)</i>
Fuzzy Front-End of the Design Process	<i>The early stages of the design process where the question/problem/brief for the design is investigated.</i>
RtD	<i>RtD (Research through Design) is the exploration of new knowledge through the practice of design and iterative reflections on this design process.</i>
My-Lymphy-Diary	<i>A reflective lymphoedema self-management journal designed for this study (Appendix F1).</i>
Wrap-to-Measure	<i>A low-tech self-monitoring tool designed for this study. It allows measuring the circumference of certain sections of the arms or legs (Section 6.1)</i>

Chapter 1 Introduction

1.1 Background

Developments in medical technologies have led to an increase in life expectancy and consequently, in the number of people living with long-term chronic conditions. In England in 2012, 58% of people over the age of 60 and 14% of people under 40 years old had a chronic condition according to the Department of Health (2012). Chronic condition management is challenging for the people living with them and costly for healthcare services (Long term conditions compendium, 2012, Buttorff et al., 2017) and necessitates more comprehensive support compared to ‘traditional’ acute healthcare. In acute care, medical professionals look after people and make healthcare decisions with patient consent. People who need acute care take on a temporary ‘patient role’ and they aspire for a recovery. In chronic conditions on the contrary, a recovery or a cure is usually not a potential outcome, and patients are expected to manage their conditions by making healthcare decisions every day for the rest of their lives. Healthcare for chronic conditions also defies the conventional definition of health as “*complete physical, mental and social well-being*” (WHO, 2006 - definition phrased in 1948). Huber et al. (2011) framed a new definition of health; and highlighted that despite the challenges brought by chronic conditions, living a healthy, meaningful and fulfilling life is possible. To achieve this, ‘self-management’ of chronic conditions is encouraged. Previous research has identified that effective self-management has the potential to provide significant benefits for quality of life of patients and for healthcare services (Research evidence on the effectiveness of self care support, 2007, Grady and Gough, 2014).

‘Patient empowerment’ has been recognised to be a priority to take the extra pressure off from healthcare services, and to improve self-management of patients by allowing them more power and control over their care (NHS, 2019, NMC, 2018). Patient empowerment is commonly defined as increased control over decision-making related to one’s healthcare (WHO, 1998). However, this approach assumes a direct correlation between greater control/power and patient empowerment, which has not been evidenced (Wyatt et al., 2010). Hewitt-Taylor (2004) asserted that, empowerment was beyond simply passing power of decision making to patients from healthcare providers. Fumagalli et al. (2015) described the importance of the motivation and the ability of patients to be able to have increased power during their relationships with healthcare professionals. Aujoulat et al. (2008) depicted patient empowerment as a ‘personal transformation’ which is not necessarily through increased ‘power’ or ‘control’.

To date there has been no common agreement on what ‘patient empowerment’ means for people living with chronic conditions themselves (Aujoulat et al., 2007, Barbosa et al., 2021, McAllister et al., 2012, Pekonen et al., 2020, Payne et al., 2013, Samoocha et al., 2010, Schneider, 2019). One of the reasons for not having a consensus on ‘patient empowerment’ is that self-management priorities of people living with chronic conditions and healthcare professionals do not always seem to be aligned. In chronic care management, healthcare professionals tend to concentrate on patient’s compliance with a certain routine and measurable health outcomes (Grady and Gough, 2014, Nakagawa-Kogan et al., 1988, Been-Dahmen et al., 2015). Conversely, for people living with chronic conditions, self-management is their life, and usually goes beyond adherence and quantifiable medical symptoms (Anderson, 1985, Anderson and Funnell, 2000, Bodenheimer et al., 2002, Trostle, 1988, Harris et al., 2010). According to Zimmerman (1995), a universal measure of ‘empowerment’ was not appropriate, because

empowerment was different “*across people, contexts, and times*”. They differentiated `empowering processes` which are participatory and enable shared decision-making, and `empowered outcomes` which are the results of these processes (Zimmerman, 1995).

`Design` as a process (design as a verb) and as an outcome (design as a noun), has the potential to facilitate or suppress patient empowerment. In this context, empowerment should be considered holistically, beyond the transfer of power from healthcare providers to patients (Hewitt-Taylor, 2004, Aujoulat et al., 2008). Underestimation of empowerment as being merely increased power in decision-making could lead to ineffective or even sometimes detrimental design solutions. Concerns have been raised that technologies claiming to be `empowering` through the provision of information and increased options have the potential to actually `dis-empower` their users by stigmatising them and increasing psychological vulnerabilities (Schneider, 2019). Self-management support systems have the potential to facilitate empowerment, but there was little evidence about the degree of empowerment the available systems were ensuring (Alpay et al., 2010). Comprehending the meaning of empowerment and its implications for the design of products/systems/services is therefore important. Patient empowerment requires a particular collaboration between patients and healthcare providers, and an in-depth understanding of the real daily lives of patients with chronic conditions. Previous reviews on existing self-management support systems discussed that the everyday real-life experiences of people living with chronic conditions were overlooked (Nunes et al., 2015, Phillips et al., 2018). Available systems have been predominantly focusing on behaviour-change by monitoring and quantifying the condition, with potentially unrealistic expectations from their users to always be motivated to prioritise self-management (Nunes et al., 2015). However, in everyday life people had limited resources and “*different interests, hobbies, values, roles, and that, by chance, happen to have a chronic condition*”

that sometimes required time and concern” (Nunes et al., 2015). There is a need for better understanding how we might design products and services that can facilitate empowerment.

In this PhD thesis, the meaning of empowerment and the question of ‘how to design for empowerment’ are investigated with people living with a chronic medical condition called lymphoedema. Lymphoedema is a chronic condition of oedema/swelling of a part of the body. It is a progressive condition unless it is managed. It can affect any part of the body, while it is commonly experienced in the arm(s) or leg(s). Symptoms of lymphoedema include excessive swelling, pain, discomfort, heaviness and increased risk of cellulitis infections. In 2012, Moffatt *et al.* estimated that 120 million people were affected from lymphoedema globally. Even though a permanent cure for this condition has not yet been found, effective management of symptoms has been shown to be possible (Grada and Phillips, 2017). Management of lymphoedema usually involves various compression therapies and massages to move the lymphatic fluid away from the limb and out from the system. Lymphoedema management can include intensive clinical treatments and application of multilayer lymphoedema bandaging to the affected limb (Wigg and Jones, 2006). Following such clinical treatments done by specialist lymphoedema therapists, a typically burdensome daily self-management routine has to be followed by *People Living with Lymphoedema* (PLWL) themselves. Every day lymphoedema self-management commonly involves wearing compression garments, and doing skin care, massages and exercises (Moffatt, 2006, Wigg and Jones, 2006). Consistent practice of self-management by PLWL has been shown to be low, and not managing lymphoedema could lead to increased oedema, pain, decreased mobility, need for recurrent clinical treatments and increased risk of cellulitis infections (Ridner et al., 2011). Empowerment of patients to help them self-manage has been prioritised in lymphoedema care (Todd et al., 2010).

However, the meaning of empowerment for PLWL, and how to design to achieve empowerment in lymphoedema self-management, are not currently clear. Hence, in this thesis ‘How might we design to support the empowerment of PLWL in their self-management?’ has been identified as the main research question.

1.2 Context

This PhD study was funded as a Research and Innovation Award from Cardiff Metropolitan University. It was conducted at PDR (International Centre for Design and Research) within the SPD (Surgical & Prosthetics Design) Group. PDR is a design consultancy and research centre within Cardiff Metropolitan University. SPD is one of the research groups within PDR, which works in collaboration with healthcare professionals for research and development of patient-specific medical devices.

The research question investigated in this thesis emerged as a result of the literature review on people’s lymphoedema experience (Chapter 2 and 4) and observations in the clinics (Chapter 5). These early investigations showed a need for a comprehensive support for everyday self-management experiences for lymphoedema.

In this PhD study, an iterative and collaborative design research process was followed as shown in Figure 1-1. The health sciences literature about lymphoedema was rich, and a systematic literature review was conducted to investigate the lymphoedema self-management experience, prior to conducting primary studies with PLWL. Primary research started with observations in the lymphoedema clinics and informal interviews with lymphoedema therapists (Section 5.1). The findings from the literature review and observations in the clinics led to the development of scenario-based probes. These scenario-based probes were used during one-to-one interviews with PLWL (Section 5.2). The findings of these interviews led to the development of a cultural probe including My-

Lymphy-Diary (a reflective self-management diary) and Wrap-to-Measure (a low-tech tool to self-monitor lymphoedema) (Section 6.1). This cultural probe was introduced to the study participants with lymphoedema during a workshop. Participants tailored and made Wrap-to-Measures for themselves during the workshop and used these with their My-Lymphy-Diaries for a period of two months (Section 6.2). As a result of these studies, `persona journeys` were developed and used during interviews with lymphoedema therapists (Sections 6.3 and 6.4).

As shown in Figure 1-1, the first three years of this PhD study was conducted as a full-time student. After January 2020 the writing of the thesis was completed as a part-time PhD student.

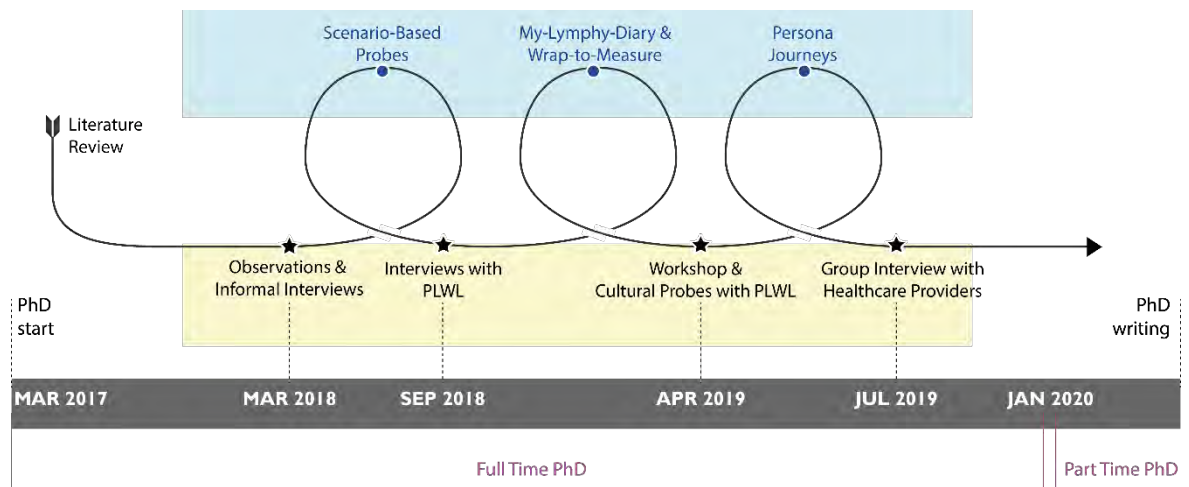


Figure 1-1 Timeline of the PhD in relation to the conducted primary studies

1.3 Contributions

In this PhD study, a new perspective on design for empowerment in self-management is proposed. Previously, in the design of self-management support systems, the changing needs of individuals while they are gaining empowerment have not been taken into consideration. Patient empowerment has usually been interpreted as handing

over decision-making responsibilities from the healthcare professionals to the patients. These approaches have overlooked some of the aspects of everyday life with a chronic condition and individuals' readiness for empowerment.

In this thesis, the meaning of empowerment, according to the PLWL has been described considering the everyday life with this chronic condition (competence, autonomy, habit, psychology, identity, support network). This study presents the stages individuals go through towards empowerment. The results have shown that individuals' self-management support needs vary, depending on their readiness for empowerment, and thus, stage-based guidelines for design are necessary. This design research study has resulted in guidelines on how individuals should be supported for empowerment in chronic condition care, and presents implications for the design of future self-management support. This thesis makes the following primary contributions to knowledge:

- 1) The meaning of empowerment for lymphoedema self-management (Table 7-1)
- 2) A model for empowered self-management, which depicts the three main stages individuals go through, and their changing support needs while gaining empowerment in their self-management (Table 5.6)
- 3) Design guidelines to enable provision of the right support at the right time to facilitate empowerment (Table 6-5 and Appendix G)

A secondary contribution to knowledge was made as a result of the design research process followed with the active involvement of PLWL: designing with `empowered patients` and the design probes used to explore their past, present and future.

1.4 Structure of the Thesis

The structure of the thesis is presented in Figure 1-2:

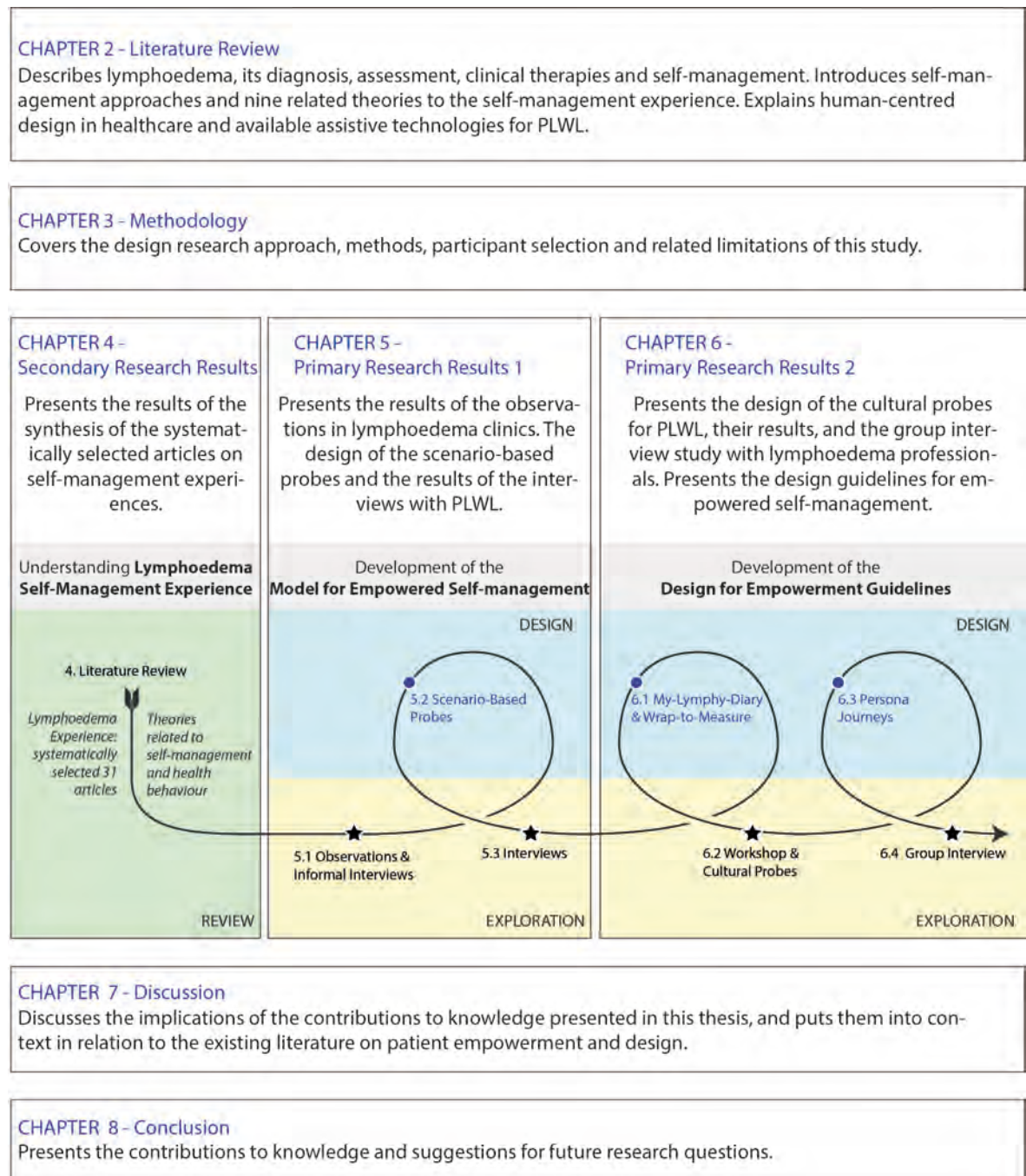


Figure 1-2 Structure of the thesis.

Chapter 2 Literature Review

This chapter presents the literature review that provided the foundation for the research questions investigated in this PhD thesis. This chapter aims to introduce lymphoedema and chronic condition self-management, and their investigation from multiple theoretical perspectives. The chapter starts by describing what lymphoedema diagnosis, treatment and self-management are. Further, approaches and theories related to chronic condition management are described. Following, design in health and wellbeing context is presented. Finally, available support systems and assistive technologies for lymphoedema management are reviewed.

2.1 Lymphoedema

Lymphoedema is a progressive and chronic swelling of a part of the body. It is caused by the excessive accumulation of lymphatic fluid in the tissues. Lymphoedema can present in any part of the body including head, neck and genitals, yet it is most commonly seen in arm(s) and/or leg(s). Lymphoedema is caused by insufficiencies in the lymphatic system. There are two types of lymphoedema: primary and secondary. The **primary** type is congenital; it can start during childhood, but could develop at any age, and there is no identifiable external cause (Mortimer, 1995). The **secondary** type is caused by damage to the lymphatic system due to injuries, trauma, poor venous function, cardiac disease, infections or, most commonly, cancer treatments (Moffatt, 2006).

Approximately 1.33 people in every 1000 people in the UK are reported to live with lymphoedema; the likelihood of lymphoedema onset increases with age and it is more common in women (2.15 women, 0.47 men /1000) (Moffatt et al., 2003). However,

Moffatt et al. (2003) asserted that the recognition of lymphoedema by healthcare professionals was low, which might cause underestimation of the actual numbers. A study in 2017, reported that 5 out of every 1000 people in Wales, UK, had the condition (Thomas and Morgan, 2017). The prevalence of primary lymphoedema is lower than secondary lymphoedema (Moffatt, 2006, Cooper, 2013). Secondary lymphoedema most commonly arises as an effect of cancer treatment: 16-28% of people going through breast cancer treatment (DiSipio et al., 2013) and 28-47% of those receiving gynaecological cancer treatment are reported to acquire lymphoedema (Moffatt, 2006, Hayes et al., 2017).

Symptoms reported by PLWL include swelling, heaviness, tightness, pain, aching, tenderness, stiffness, weakness, numbness and reduced range of movement (Finnane et al., 2015). Moffatt et al. (2003) found that half of the 228 PLWL they interviewed reported uncontrolled pain and 80% had to take time off from work due to lymphoedema, while 8% had to stop working completely (Moffatt et al., 2003). Moreover, PLWL were reported to have increased susceptibility to acute cellulitis (a bacterial skin infection). Commissioning Guidance for Lymphoedema Services for Adults in the United Kingdom stated that having more than one episode of cellulitis was a sign of a failure in lymphatic drainage in that limb (NLP, 2019). As quoted by Levell et al. (2011) cellulitis caused overall 400,000 days of hospital stays per year in the English National Health Service (NHS) at a cost of £96 million. Moffatt et al. (2003)'s study showed that one third of their participants with lymphoedema had suffered a cellulitis infection during the year prior to the study. One third of these with cellulitis related to lymphoedema was administered intravenous antibiotics which required inpatient care for around 12 days (Moffatt et al., 2003). Burian et al. (2021) evidenced that management of oedema was significantly decreasing the risk of cellulitis for PLWL.

2.1.1 Lymphoedema Diagnosis and Assessment

Lymphoedema is a progressive condition and if not managed it can become more severe. Four stages of severity in lymphoedema have been defined (ISL, 2013, Moffatt, 2006, Nazarko, 2022):

Stage 0 (subclinical): No evident swelling yet, but impaired lymphatic system and some changes in tissue and fluid composition

Stage I (mild): Early accumulation of lymphatic fluid in tissues which reduces when the limb is elevated. When the skin is pressed a temporary pit is formed (pitting oedema). More than 20% excess volume increase in the affected limb(s).

Stage II (moderate): Elevation alone rarely reduces the oedema. Pitting oedema may or may not be seen depending on the fat and fibrosis in the tissues. Between 20% to 40% excess volume increase in the affected limb(s).

Stage III (severe): Skin changes, fibrosis, folds and overgrowths are apparent. Pitting can be absent. More than 40% excess volume increase in the affected limb(s).

Early diagnosis and treatment is essential to avoid the deterioration of the condition (NLP, 2019). However, lymphoedema can be difficult to differentiate from other types of oedema especially in its early stages (Grada and Phillips, 2017). Medical assessment is usually performed by general practitioners before any referral to specialists, which involves physical examination and medical history check (Moffatt, 2006). These assessments could be complemented with medical imaging and genetic testing to achieve a clear diagnosis (ISL, 2013, Suami et al., 2012). Nevertheless, a study conducted in 2003 in the UK (with 823 participants living with chronic oedema), showed that only around 4% of the participants went through specialist assessments for lymphoedema diagnosis, half of their participants had never been told about the reasons of their chronic oedema and 36%

did not receive treatment (Moffatt et al., 2003). Szuba et al. (2003) asserted that lymphoedema was commonly overlooked by physicians; 60% of their patients self-initiated their request for lymphoedema evaluation without any referral from healthcare professionals, even though they had lymphoedema for several years. A study conducted among General Practitioner Doctors in Scotland showed that 86% of the respondents did not have any education about lymphoedema (Davies et al., 2012). Nairn et al. (2019) discussed that lymphoedema had low-priority and low-status within healthcare systems, which contributed to the prolonged periods before diagnosis for many. According to Ridner et al. (2012), many PLWL perceived their clinical treatment poorly compared to the management of other chronic conditions.

Lymphoedema assessment is usually carried out by practitioners with specialist training (NLP, 2019). Lymphoedema assessment is done for diagnosis, and also periodically throughout lymphoedema treatment and management (Moffatt, 2006, NLP, 2019). This includes assessment of swelling volume, skin condition, vascular status, pain, nutrition and psychosocial elements (Moffatt, 2006). If only one of the limbs are affected from lymphoedema (unilateral) both limbs are measured and the difference between their volumes is tracked as an indication of excess fluid (Moffatt, 2006). When both limbs are affected (bilateral), these are measured to track the changes in volume over time (Moffatt, 2006). The following are the methods used for assessing oedema and measuring limb volume in lymphoedema (Figure 1):

a - Water displacement method: This method is considered as the gold standard in volume measurement because of its accuracy (Lette et al., 2007). It relies on the Archimedes principle that an object displaces water that is equal to its volume. The limb (arm or leg) is submerged into a tank full of water and the excess water that the limb displaced is measured. Even though considered to be very accurate in measuring the

volume, because of the practical issues about using a tank full of water and hygiene, the use of this method is limited (Moffatt, 2006, Lette, 2006, Damstra and Partsch, 2009).

b - Circumferential limb measurements: This method is the most widely used method, because it is easily accessible and considered reliable when an adequate protocol is followed. It involves measuring circumferences of the affected limb at certain sections. In order to calculate the volume change from these measurements in lymphoedema practice usually specialist computer programmes are used (Moffatt, 2006, Brorson and Höijer, 2012).

c - Perometry: This method involves the use of infrared light to measure the outline of the limb. It is an accurate and quick method, but its use is limited in practice because of the cost of the required equipment (Stout Gergich et al., 2008).

d - Bioimpedance: This method uses the difference the tissues show resistance to electrical current (impedance ratio), in order to indicate the volume of the extracellular fluid. It is not an established method in routine practice, but is proved to be useful for the identification of lymphoedema at subclinical level (stage 0) while the swelling is not yet evident (Hayes et al., 2005, Qin et al., 2020, Ridner et al., 2014a).

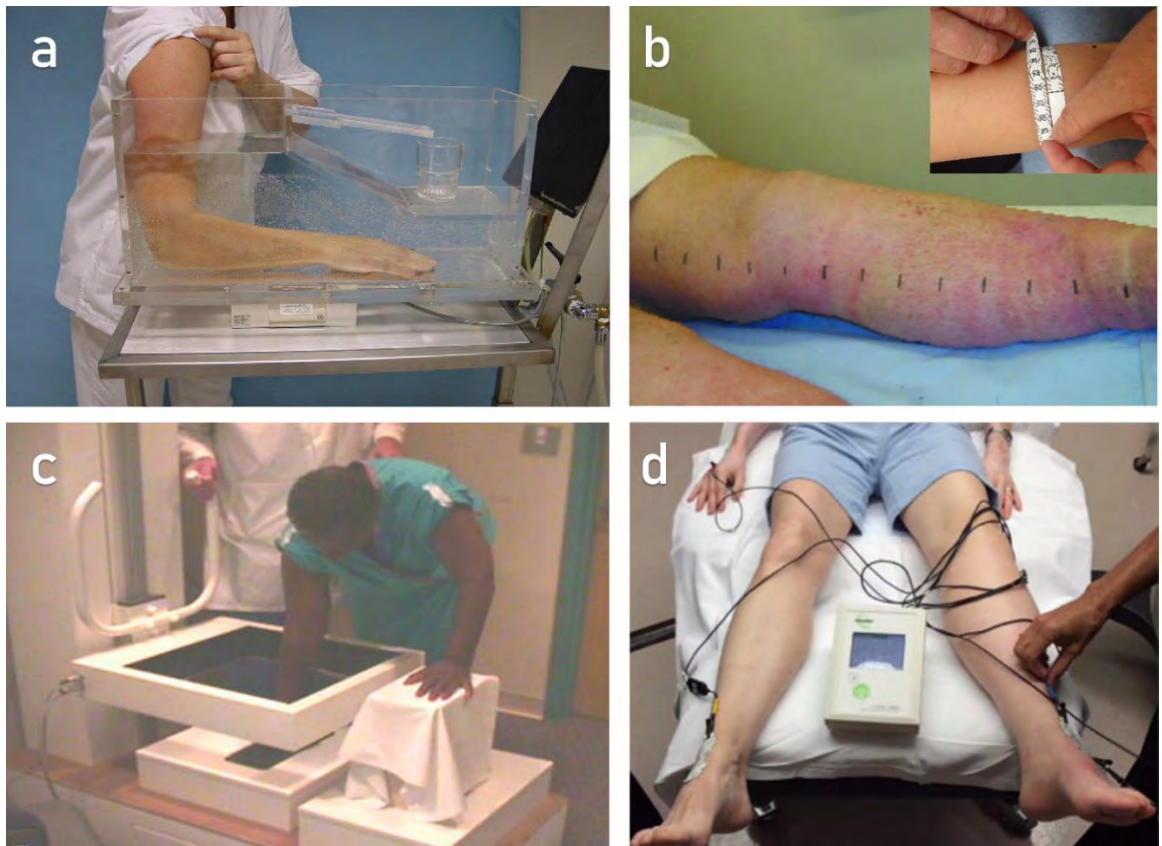


Figure 2-1 a- Water displacement method (Damstra and Partsch, 2009) b- Circumferential limb measurements (Moffatt, 2006, Noble-Jones et al., 2021) c- Perometry (Stout Gergich et al., 2008) d- Bioimpedence (Qin et al., 2020)

Lymphoedema cannot be definitively cured yet, but its progression and complications can be managed (Grada and Phillips, 2017, Nazarko, 2022). The treatment decisions for lymphoedema are made following a holistic assessment (Moffatt, 2006). If the lymphoedema is late moderate (Level II: 20-40% excess volume) or severe (Level III: more than 40% excess volume) usually a **Complete Decongestive Therapy (CDT)** is followed. CDT is accepted as the standard for lymphoedema treatment (Lasinski, 2013). As shown in Figure 2.2. CDT consists of two phases: intensive therapy and long-term management.

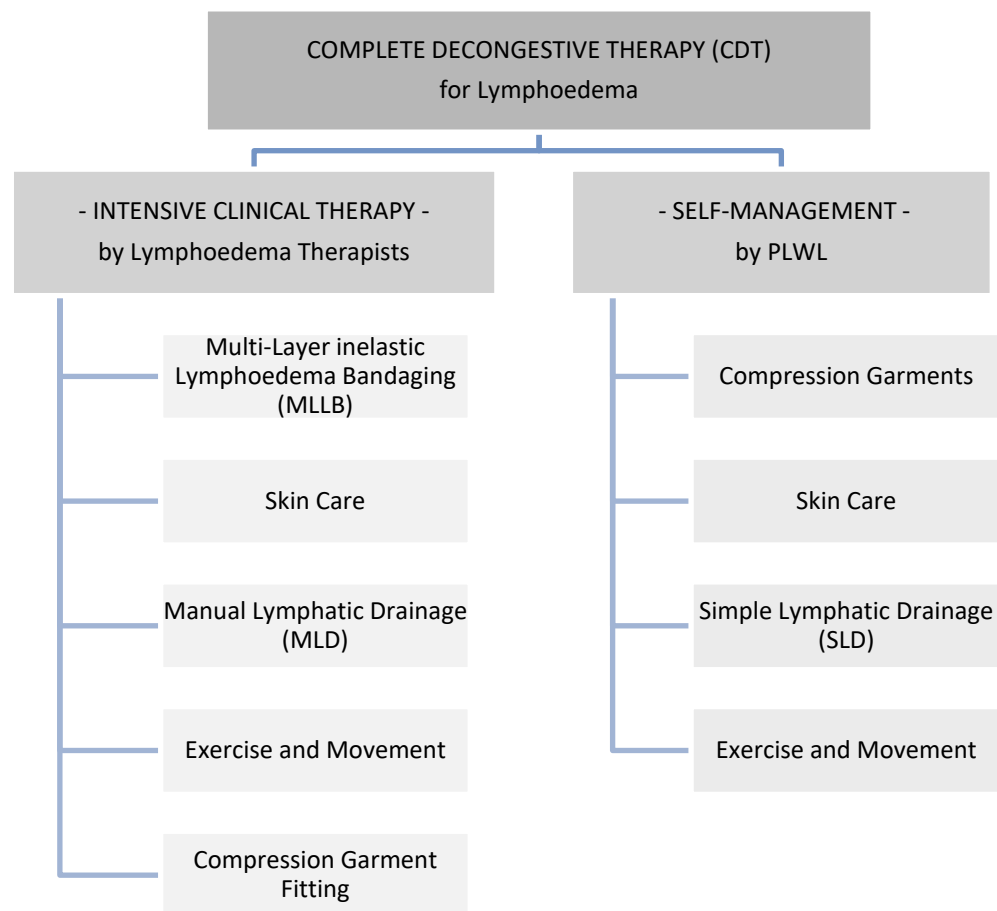


Figure 2-2 Complete Decongestive Therapy (CDT) for Lymphoedema: Intensive Clinical Therapy and Self-Management

2.1.2 Intensive Clinical Therapy of Lymphoedema

Intensive clinical therapy is carried out to reduce swelling, improve limb shape, tissue and skin condition if needed (Moffatt, 2006, Lasinski, 2013). The intensive phase is carried out daily by a lymphoedema therapist for around 2-4 weeks:

- **Multi-Layer inelastic Lymphoedema Bandaging (MLLB):** MLLB is a bandaging technique (Figure 2.3) to create graduated compression to the limb in order to restore shape, soften tissue and reduce skin changes (Moffatt, 2006, Lasinski, 2013).

Graduated compression provides pressure that is the highest at the farthest point of the

limb and decreases towards the heart. This graduated compression supports the pumping of the lymphatic fluid towards the body (NLP, 2019).

- **Skin care:** Monitoring skin is important to identify any developing skin conditions and abrasions. The skin is washed and dried, and emollients are applied (Moffatt, 2006).
- **Manual Lymphatic Drainage (MLD):** MLD is a gentle massage technique to increase activity in lymphatic system to move the fluid away (NLP, 2019). Ideally, an hour of MLD is advised daily during intensive therapy to stimulate the lymphatic pumping (Lasinski, 2013).
- **Exercise and Movement:** Exercises enhance lymphatic pumping and help managing the oedema (Lasinski, 2013).
- **Compression Garment Fitting:** As a preparation to the self-management phase of CDT, measurements are taken and an appropriate compression garment is fitted to maintain the volume reduction achieved during the intensive treatment (Lasinski, 2013, Moffatt, 2006).



Figure 2-3 Multi-Layer inelastic Lymphoedema Bandaging MLLB to the lower leg (Moffatt, 2006)

If non-operative treatments are not effective, surgical treatments may be considered including reduction operations to remove excess tissue, liposuction to remove excess fat tissues and bypass surgery to restore lymphatic function such as Lymphatic Venous Anastomosis (LVA) surgery (Moffatt, 2006, ISL, 2013). LVA is a super-

microsurgery to connect the damaged lymphatic vessels to a vein. That allows lymph fluid drainage into the blood and reduces the related lymph swelling. It has been shown that after the surgery 70% of PLWL are able to stop wearing their compression garments (Carroll et al., 2015). However, in order to maintain the results of surgical treatments a continuation of compression therapy and self-management is usually advised (Moffatt, 2006).

2.1.3 Self-Management of Lymphoedema

Long-term self-management is necessary to maintain the results of intensive therapy and to prevent the increase of the swelling and the symptoms of lymphoedema. Four main strategies are recognised as the cornerstones of lymphoedema self-management:

- **Wearing compression garments:** There are many types of compression garments that differ in pressure and construction, these are advised to be fitted by trained lymphoedema therapists following a holistic assessment (Moffatt, 2006, Ohlin et al., 2015). Compression garments help control the swelling and decrease the oedema (NLP, 2019, Vignes et al., 2007). According to Lam et al. (2006)'s study, 86% of compression garment wearers perceived their garments to be successful in managing their lymphoedema, yet one in every 7 participant had stopped wearing them. Frequently mentioned reasons for discontinuation were increased pain and discomfort, problems with the fitting, seeing no benefits, swelling around the garment, skin intolerance and hot weather (Lam et al., 2006).
- **Doing exercises and movements:** Movement and exercise helps to increase the range of movement of the limb and flow of lymph fluid (NLP, 2019, Jeffs and Wiseman, 2013). Despite limited evidence about the type and intensity of an effective exercise

programme, muscle pumping exercises are advised for lymphoedema self-management, especially when the compression garments are being worn (Moffatt, 2006, ISL, 2013).

- **Performing skin care:** Skin care involves 1) daily washing, drying and moisturizing, 2) preventing cuts and breaks, and 3) monitoring the skin for any changes and signs of cellulitis infection (NLP, 2019, Todd, 2013). PLWL are advised to monitor changes in their skin for the early signs of complications like cellulitis (Moffatt, 2006).
- **Doing Simple Lymphatic Drainage (SLD):** SLD is a simplified version of MLD that is advised to be practiced daily by patients or their carer at home (Moffatt, 2006). SLD helps the flow and drainage of the lymph flow (NLP, 2019, Todd, 2013).

During the self-management phase, PLWL are advised to see their lymphoedema therapists every six to twelve months for follow-up and to have their limbs re-measured for a compression garment fitting (Moffatt, 2006).

Despite the emphasis on formal lymphoedema self-management education by therapists (Ridner et al., 2011), studies have shown that PLWL utilise a variety of sources for learning self-management. As reported by Deng et al. (2013) the most frequently mentioned sources of information among PLWL were websites (76%), healthcare providers (55%), online support groups (33%) and family (32%).

Poor management of lymphoedema may result in recurrent clinical treatments, increased swelling, poor quality of life and increased likelihood of complications such as cellulitis infections and fibrosis (Deng et al., 2015, Morgan et al., 2005). A study conducted in Germany showed that on average the total cost per patient with lymphoedema per year was around €5,500, in which intensive therapy and disability costs were driving the majority (Gutknecht et al., 2017). Gutknecht et al. (2017) asserted that early diagnosis

and effective management programmes were important to decrease the costs associated with complications and to increase people's quality of life. However, previous research has shown that consistent daily self-management practice is low among PLWL (Deng et al., 2015, Ridner et al., 2011). Among the respondents with lymphoedema who received compression garments, approximately one third of them never wore them (Moffatt et al., 2003).

2.1.4 Transition to Self-Management

The intensive clinical therapy of lymphoedema involves bulky bandages which drastically restrict people's daily lives during the treatment (Williams et al., 2004). Still, many PLWL described being even more anxious about the end of their intensive therapy, after which they would be managing it at home and without the assistance of their therapists (Ridner et al., 2016; Williams et al., 2004). Despite its restrictions, during intensive therapy the improvements can be monitored, and therapists are present to support and encourage PLWL on a day-to-day basis. However, during the self-management phase, PLWL describe the difficulty in prioritising self-management besides the other ongoing responsibilities in life and not seeing any benefits despite following the management strategies (Radina et al., 2014, Jeffs et al., 2016). The self-management phase has been reported to be a phase where PLWL found the instructions provided difficult to follow (Fu et al., 2010). PLWL describe feeling disheartened by the need to manage their condition daily themselves with frustrating compression garments, instead of being taken care of by therapists (Karlsson et al., 2015). Tidhar and Armer (2018) contended that the lack of clarity in the transition from intensive therapy to long-term self-management led PLWL to perceive self-management as an abandonment by their healthcare system (Figure 2-4).

Armer et al. (2011) asserted that PLWL perceived self-management support to be mostly limited to delivery of information, which did not ensure understanding or action. Hence, it has been emphasised that there is a need for more comprehensive support to support the transition to self-management (Armer et al., 2011).

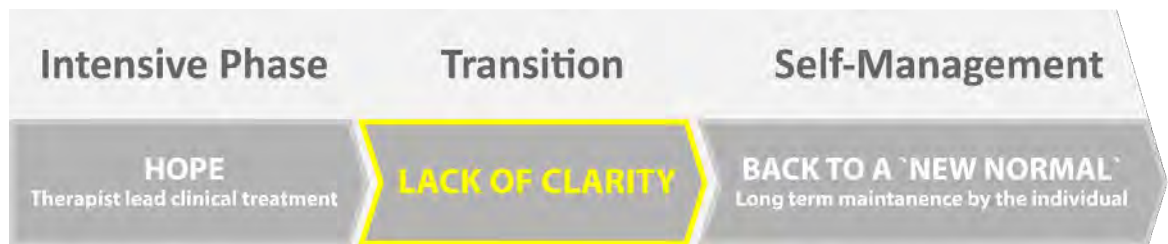


Figure 2-4 Lack of clarity in the transition to self-management adapted from Tidhar and Armer (2018).

Approaches to self-management and the meaning of collaborative care are presented in the following section.

2.2 Traditional Care versus Collaborative Care Approaches to Self-Management

"All patients wish to care for themselves" (Orem, 2001)

The traditional care approach focuses on the body of the patient, the disease and its biomedical causes (Munro, Lewin, Swart, & Volmink, 2007). Within this approach, health may be defined as *"the absence of disease or infirmity"*. This definition was first formulated in 1948 and stayed as the mainstream until 2006, when WHO (World Health Organisation) updated this definition and included physical, mental and social aspects: *"Health is a state of complete physical, mental and social well-being"* (WHO, 2006). Despite this definition being more inclusive, it has been criticised, because `complete` is not measurable and it implies that a large proportion of people, including those with chronic conditions are unhealthy (Huber et al., 2011). Huber et al. (2011) emphasised that

despite the physical, mental and social challenges faced by people living with chronic conditions, they could have wellbeing and high-quality of life. According to Huber et al. (2011) health was not an objective itself, but an agency towards a meaningful and fulfilling life. They formulated a new definition of `positive health`:

“The ability to adapt and self-manage in the face of social, physical and emotional challenges” (Huber et al., 2011).

This definition centralised the capacity to cope, adapt and self-manage. Indicators of positive health were collated and this `positive health` definition was evaluated by healthcare professionals, policymakers and people with chronic conditions (Huber et al., 2016). While healthcare professionals’ description of health has traditionally focused on the bodily functions and quality of life, patients mentioned more broad and holistic indicators of health including social, existential and mental aspects (Huber et al., 2016). Evidently, health implies different meanings and connotations for healthcare professionals and patients.

In the traditional care approach, healthcare professionals are perceived to be responsible for telling their patients what to do to achieve a “state of physical, mental and social well-being” and focus is on the patient’s compliance with this prescribed treatment (Bodenheimer et al., 2002). Within this perspective, adherence has been perceived to be related to the demographic characteristics of individuals (Edwardson and Dean, 1999) or their attitudes and beliefs (Blackwell, 1992). According to WHO, as reported in 2003, nearly fifty percent of people with chronic diseases had poor adherence to their treatment and that was considered one of the main reasons for lack of health (Sabaté, 2003).

Increasing `patient adherence to self-management` as a measure and a challenging objective was mentioned in numerous studies about lymphoedema and beyond (Brown et al., 2015, Sabaté, 2003, van Dulmen et al., 2007, Ostby and Armer, 2016). However,

adherence implies a health behaviour without self-determination (I am doing it because someone told me to do so) (Ryan and Deci, 2000). Self-management following an adherence approach could be difficult for the patients to sustain in the long term, because this could lack being meaningful and significant for the individuals themselves (Aujoulat et al., 2007, Anderson and Funnell, 2000). Still, a study conducted in 2005 in the UK, showed that healthcare professionals were more likely to take a compliance to self-management approach with their patients (Rogers et al., 2005). WHO emphasised the importance of patient's active involvement in decision-making and "agreement on the provided recommendation" for the adherence and distinguishes the term from compliance (Sabaté, 2003). However, it was argued that this modification was insufficient and the 'adherence' approach still caused tensions between the patient and the clinician, therefore a shift to a 'collaborative' approach has been discussed (Anderson & Funnell, 2000; Bodenheimer, Lorig, Holman, & Grumbach, 2002). According to Anderson and Funnell (2000) different from acute illnesses, patients are the ones who "make the important choices", "have control" and "get the consequences" in chronic conditions. Hence, patients describe changing their lives in response to orders from healthcare professionals as difficult, instead they raise a desire to be supported to solve problems and take responsibility in managing their own condition (Bodenheimer et al., 2002). Where in a traditional approach some demographics and characteristics of individuals are considered less likely to adhere to treatments (Edwardson and Dean, 1999), in a collaborative approach everybody is considered to have the intention and potential to care for themselves (Orem and Taylor, 2011). Orem (2001)'s nursing theory of self-care is based on the belief that "all patients wish to care for themselves" and focus on holistic care instead of just the treatment of acute injuries. According to Orem it is important to allow the patient to self-manage to the best of their ability, and for the nurse to adapt their care within this dynamic situation and

support them whenever the patient needs help (Katherine Renpenning and Taylor, 2003). This approach is human-centred, and prioritise the goals and aspirations of the patient instead of their `body` in medical terms.

Alcorso et al. (2016) presented the differences between the perception of adherence to self-management by lymphoedema therapists and patients. While therapists believed certain barriers to self-management were likely to impede individuals' adherence, patients disagreed with these (Alcorso et al., 2016). This highlighted a mismatch between therapist and patient perspectives to adherence in lymphoedema self-management. Another study suggested that adherence to self-management did not predict change in oedema (study was conducted with people with breast cancer related lymphoedema for a 12 month duration) (Brown et al., 2015). The benefits of these self-management strategies to lymphoedema symptoms were previously evidenced (Brennan and Miller, 1998), yet `adherence` to these as a measure of success was not found to be effective in that study (Brown et al., 2015).

Bodenheimer et al. (2002) compared the traditional and collaborative care approaches, by emphasising the shift of the responsibility of healthcare providers from performing care to coaching and collaborating with people with chronic conditions (Table 2-1).

From a collaborative care perspective, instead of traditional health outcomes (e. g. symptom management, health-related quality of life, functions) `patient empowerment` was discussed to be an important element for supporting self-management (Holmström and Röing, 2010, McAllister et al., 2012). In the UK, National Health Services (NHS, 2019) and The Nursing and Midwifery Council (NMC, 2018) identified `patient empowerment` as central for chronic condition management.

Table 2-1 Comparison of Traditional and Collaborative Care in Chronic Condition Self-Management adapted from Bodenheimer et al. (2002).

	TRADITIONAL CARE	COLLABORATIVE CARE
Relationship between patient and health professionals	Professionals are the experts who tell patients what to do. Patients are passive.	Shared expertise with active patients. Professionals are experts about the disease and patients are experts about their lives.
Goal	Compliance with instructions. Noncompliance is a personal deficit of the patient.	The patient sets goals and the professional help the patient make informed choices. Lack of goal achievement is a problem to be solved by modifying strategies.
Responsibility in identification of problems, solving these and the related outcomes	Professionals are responsible for identifying problems and solving these for patients.	The patient and professional are the principal caregivers; they share responsibility for identifying problems, solving these problems and for outcomes. Professionals teach problem-solving skills and help patients in solving problems.
Source of motivation for health behaviour changed	External motivation.	Internal motivation. Patients gain understanding and confidence to accomplish new behaviours.

A collaborative human-centred care approach has been chosen for this PhD study, and this has influenced the formulation of the research questions, chosen research methods and the design research process. In the following section, theories related to self-management experience are presented in relation to lymphoedema experience.

2.3 Self-Management Experience and Related Theories

Understanding and theorising the health behaviour of people (how and why they act in certain ways about their healthcare) has been a long endeavour aiming to guide interventions and policies. Yet, previous research has shown that designers have not fully utilised such established multidisciplinary knowledge and most healthcare technologies

have been developed without considering any such theoretical groundings (Nunes et al., 2015, Sawesi et al., 2016, Riley et al., 2011). Riley et al. (2011) asserted that health behaviour theories are not readily implementable nor well-suited for the new adaptable and dynamic health interventions. Nunes et al. (2015) have discussed that design has been mostly limited to investigating the use of technology in self-management. Health, sociology, psychology and nursing studies present opportunities to better understand individuals' everyday life with a chronic condition; however, this opportunity has been underutilised in design (Nunes et al., 2015).

Table 2-2 Theories Related to Self-Management

Learning Theories	Behavioural & Cognitive Theories	Adaptation Theories	Socio-Psychological Theories
2.3.1. Skill Acquisition Theory (Dreyfus and Dreyfus, 1980)		2.3.8. Patient Health Engagement (Menichetti and Graffigna, 2016)	2.3.9. Biographical Disruption (Bury, 1982)
2.3.5. Self-Efficacy and Social Learning Theory (Bandura, 1977)			
2.3.2. Experiential Learning Theory (Kolb et al., 2001)	2.3.4. Self Determination Theory (Ryan and Deci, 2000)		
	2.3.3. Stages of Change (Prochaska and DiClemente, 1983)	2.3.6. Five Stages of Grief Theory (Kübler-Ross & Kessler, 2005)	
	2.3.7. Patient Activation (Hibbard et al., 2004)		

A variety of theories on health behaviour, cognition, adaptation, psychology and nursing have been investigated as a part of this literature review. The literature search aims to build a theoretical understanding of why and how people behave in certain ways related to their healthcare. In this section, a review of the nine theories related to self-management

behaviour is presented (Table 2-2). These theories were investigated simultaneously while reading the literature on the self-management experience of PLWL. This allowed for distinguishing the theories fitting the nature of lymphoedema management. The first seven theories presented are well-established and widely cited, describing human behaviour in general. The final two theories are developed in the 2000s and are particularly about chronic condition self-management. These theories, and how they compare with the lived experience of lymphoedema self-management are presented in the following sections:

2.3.1 Self-Management as Skill Acquisition

Self-management of lymphoedema involves developing many disease-specific skills such as wearing compression garments, doing massage, skin care and exercise. Hence, self-management requires learning such new skills. Literature also evidenced the influence of broader skills on self-management, such as problem detection, decision-making, resource utilisation and problem-solving (Lorig and Holman, 2003, Lippa et al., 2008). According to skill acquisition theory, such learning could be through instructions, practice and experience (Dreyfus and Dreyfus, 1980). Dreyfus and Dreyfus (1980)'s theory proposes stages that people pass through while acquiring new skills (Figure 2-5).



Figure 2-5 Five stages of skills acquisition adapted from Dreyfus and Dreyfus (1980)

According to Dreyfus and Dreyfus (1980) at the **novice** stage the learner is adherent to the instructions and rules provided, without practicing personal judgment in specific situations. Such a novice phase in lymphoedema self-management was evident in the literature: PLWL describe following self-management instructions without fully

understanding how these were affecting their lymphoedema symptoms (Meiklejohn et al., 2013, Fu, 2010, Greenslade and House, 2006, Jeffs et al., 2016, Ridner et al., 2012, Williams et al., 2004). One of the participants of Fu (2010) explained: *“I thought that my therapist gave me very clear instructions to follow when I finished my first round of therapy. But once I was on my own I found the reality so different”* (Fu, 2010).

Competence is acquired by contextualisation of the instructions with real world examples and practices, yet situational perception and prioritisation are considered to be limited at this stage (Dreyfus and Dreyfus, 1980). PLWL described a similar level in learning while they were starting to feel the influence of their self-management to the symptoms, though without fully comprehending whether or not they were doing these effectively and how specifically these affected them (Bogan et al., 2007, Jeffs et al., 2016).

Proficiency requires experience in a wide variety of situations, and allows for recognition of similar situations for future planning (Dreyfus and Dreyfus, 1980). PLWL explained the methods they developed to cope with out-of-routine situations such as holidays, flights and days requiring the frequent use of the affected limb (Ridner et al., 2012, Williams et al., 2004).

Expertise has been described as a level where people are able to respond to situations and make intuitive or ‘deliberative rationality’ decisions (Dreyfus and Dreyfus, 1980, Dreyfus, 1982). PLWL expressed a level of expertise in self-management skills where they were intuitively following a routine, and confident about detecting and managing fluctuations when out-of-routine circumstances came out (Barlow et al., 2014a, Jeffs et al., 2016, Meiklejohn et al., 2013, Ridner et al., 2016).

According to this skill-development perspective, delivered information and individual’s experience with these enable individuals to learn and eventually practice self-management. For design, this perspective to self-management implies the importance of

the information provision and encouraging individuals to experience self-management routinely and in a variety of circumstances to facilitate recognition of similar situations through self-monitoring.

2.3.2 Self-Management as Experiential Learning

In behavioural and cognitive learning theories such as Dreyfus and Dreyfus (1980)'s Skill Acquisition Theory, learning is assessed by the competencies and it was assumed that more practice makes the learner more competent. Kolb (1984)'s Experiential Learning Theory proposed that practice and experience alone were not enough to learn. Active reflection on that experience was essential for learning. According to Kolb (1984) *"knowledge is created thorough the transformation of experience"* (p.41).

In lymphoedema self-management, information gained from therapists were appraised alongside the strategies patients developed themselves by experience and trial & error (Deng and Murphy, 2016, Jeffs et al., 2016, Karlsson et al., 2015). Kolb et al. (2001)'s experiential learning theory focuses on such subjective experiences as central to learning and is shown in Figure 2-6.

Experiential learning cycle starts with **concrete experiences**. Then, these concrete experiences are reviewed by the learner at the **reflective observation** stage (What happened? How do I feel about that?). These form the basis for **abstract conceptualisation**, where the learner thinks through and gain new knowledge by internally examining the observed experience (Why that happened?). Then, that knowledge is tested in the **active experimentation** stage (Does that really work? What can I do the next time?). This testing and verification allow learning, and lead to a new behaviour.

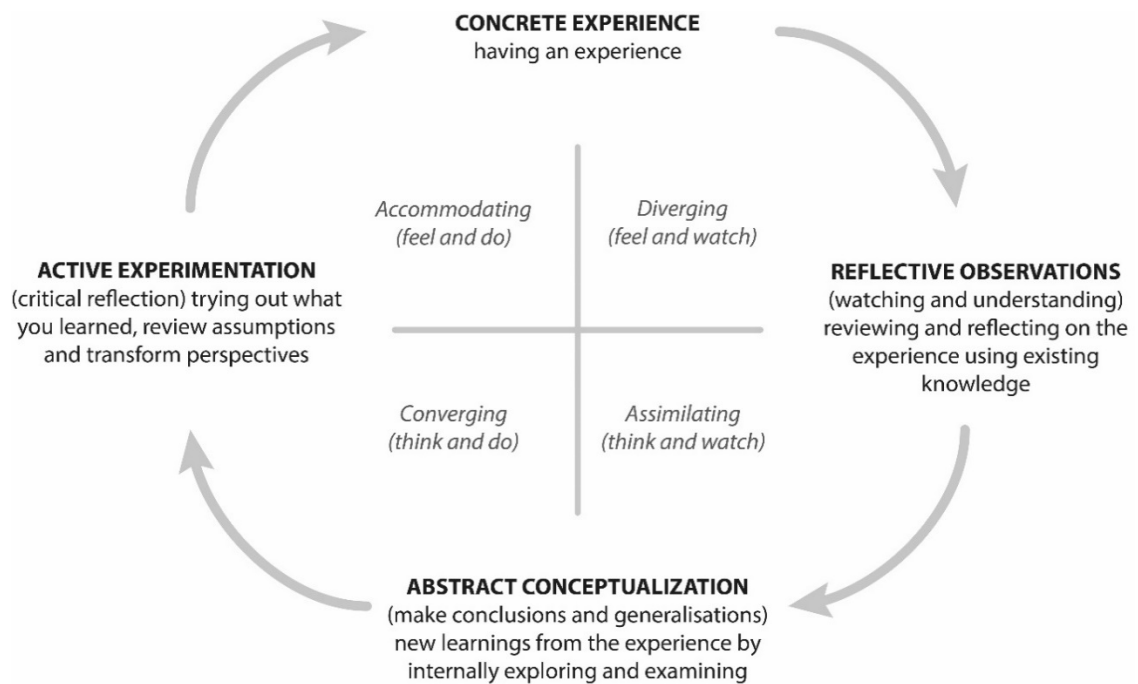


Figure 2-6 Experiential learning cycle adapted from Kolb et al. (2001)

Such active experimentation was expressed frequently by PLWL as described in the literature. For example, one of the participants in the study conducted by Jeffs et al. (2016) explained noticing internal sensations as early warning signs before experiencing an increase in swelling during busy days. They described their experiment in “*taking early action*” and adapting self-management according to such sensations (Jeffs et al., 2016). This strategy was not formally prescribed as a part of self-management education, nor were these sensations described elsewhere. However, the individual living with lymphoedema observed, tested and perceived that as an onset of fluctuations, which allowed them to develop strategies to overcome such fluctuations. Similarly, in Karlsson et al.’s (2015) study, one participant explained that they were sometimes being ‘careless’ about their self-management, yet was confident about putting their lymphoedema in the right direction again. PLWL described that everyone’s lymphoedema was unique and self-management

was a process of finding the strategies that gave them the desired benefits (Karlsson et al., 2015). Jeffs et al. (2016)'s participant explained: *"I leave it off if I'm going out or for whatever reason, but I wouldn't leave it off if I was lifting, if I was doing anything that involved putting pressure on it"*.

Experiential learning in self-management implies recognition of `what works for` the patient rather than the grounded medical principles. For that reason, experiential learning has been frequently underestimated in literature related to chronic condition care (Price, 1993). Though, Price (1993)'s qualitative study with people living with diabetes highlighted that the lived experience of self-management was a dynamic process of recognition of patterns and active experimentation to find better ways to self-manage. The voices of PLWL as expressed in the literature evidenced a similar attitude towards active experimentation of self-management strategies (Karlsson et al., 2015, Jeffs et al., 2016, Deng et al., 2016, Ridner et al., 2016, Tsuchiya et al., 2012).

According to experiential learning perspective, individuals' reflection and experiments were essential for learning. For design, this perspective to self-management implies a shift from the provision of set instructions to PLWL. This perspective highlights the importance of encouraging an active experimentation with various self-management strategies, everyday monitoring and facilitation of reflection on the influence of these strategies to individuals' symptoms.

2.3.3 Self-Management as Change in Behaviour and Habit Building

Self-management of lymphoedema requires changes in behaviour, habits and everyday routines. According to Ajzen (1985) intention is a prerequisite for change in behaviour. Yet, a desire to change behaviour has not always been enough to start new

routines required from self-management (Berg et al., 2011). Having an intention to change behaviour, to actually practicing that behaviour, requires both volitional control and automatic habitual controls led by habits (Webb and Sheeran, 2006, Triandis, 1977). The stages of change model proposed by Prochaska and DiClemente (1983) has demonstrated the stages followed for health behaviour change (Figure 2-7).

Stages of Change	Pre-C.	Contemplation	Pre-action	Action	Maintenance
<i>Prochaska & DiClemente 1983</i>	no intention for change	considering future action	have a plan for action	practice the new behaviour	keep performing the behaviour
<i>Ludden & Hekkert 2014</i>	raising awareness		enabling	motivation	fade-out

Figure 2-7 Stages of Change, adapted from Prochaska and DiClemente (1983); Stage-matched design strategies adapted from Ludden and Hekkert (2014).

The stages prior to `action` illustrate where individuals are developing the intention for change and formulating a plan for that action (Prochaska and DiClemente, 1983). This stage was evident in the experience of PLWL where they expressed their reluctance for changing their routines and the everyday restrictions lymphoedema brought to their life (Ridner et al., 2012, Fu, 2010). Some PLWL described the difficulties in taking action despite their awareness and intention (Jeffs et al., 2016, Ridner et al., 2012).

After the actual practice of the new actions, the maintenance phase is experienced (Prochaska and DiClemente, 1983). Prochaska and DiClemente (1983) highlighted that maintenance phase is still an `active stage of change` and included resistance to relapse. PLWL explained that building a daily routine allowed them to do more self-management while thinking less about it and alleviated the effects of lymphoedema on their life (Jeffs et al., 2016, Bogan et al., 2007). Yet, relapses in sustaining a daily routine of self-management were also common: *“I've been having a hard time keeping to a schedule for my arm. I would try a week or so then I would mess up with the schedule”* (Fu, 2010).

According to the ‘stages of change’ perspective, different strategies are needed to encourage behaviour change depending on individuals’ readiness for change and the stage they are at. Ludden and Hekkert (2014) described design strategies aligned with these stages as shown in Figure 2-7. For people at ‘pre-action’ stages, raising awareness were identified to be needed. That implies highlighting the importance and benefits of self-management for lymphoedema. ‘Enabling’ design strategies are advised for supporting individuals who were willing to change, to literally practice that change and made healthy choices (Ludden and Hekkert, 2014). ‘Enabling’ strategies imply sending cues and nudging the individual to encourage action. After the new behaviour has been practiced and begins to be maintained, design strategies to motivate the individual to sustain that behaviour are suggested (Ludden and Hekkert, 2014). That implies reminders and making the benefits gained through self-management apparent. Finally, a fading out phase for the intervention is suggested with careful attention to not cause a relapse in behaviour (Ludden and Hekkert, 2014). This perspective emphasises the importance of the changing motivational needs of individuals and implementing design strategies that match their stage. PLWL as described in the literature not only showed particular stages in their behaviour change, but also aspects including self-determination, competence, self-efficacy and acceptance. These are discussed in the following sections.

2.3.4 Self-Management as Self-Determination

It's not that people are unwilling to change, it's that people are unwilling to be changed. (Anderson and Funnell, 2000)

Motivation is an important part of self-management, but has been identified as hard to sustain by PLWL (Ridner et al., 2011). Ryan and Deci (2000) have differentiated autonomous/intrinsic and controlled/extrinsic motivation on someone’s behaviour.

Autonomous motivation is experienced when people feel in control and are willing to do something by genuine interest in or assigned value for something. For example, in lymphoedema, wearing compression garments would be an autonomous behaviour if that was the individual's decision, they believed it was helpful, they were committed to manage their lymphoedema or were feeling better when doing so. In contrast, external motivation would be if they were wearing compression garments because their therapists or family members told them to do so. Ryan and Deci (2000) have discussed that for sustained behaviour change the type of motivation (autonomous/intrinsic or controlled/extrinsic motivation) was a more significant influence than the extent of motivation. Ryan and Deci (2000)'s Self-Determination continuum from extrinsic to intrinsic motivation is shown in Figure 2-8.

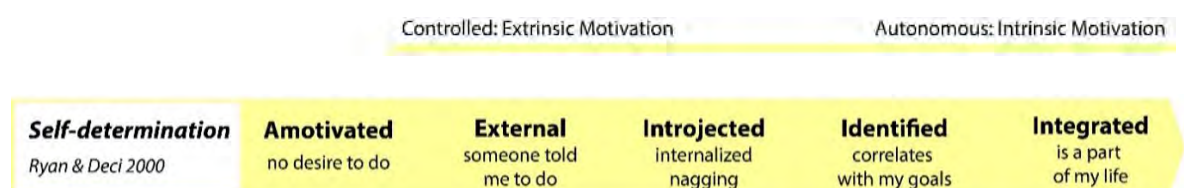


Figure 2-8 Self-Determination continuum adapted from Ryan & Deci, (2000).

Amotivation could be caused by lack of competence in accomplishing or not valuing the outcomes (Ryan and Deci, 2000). According to Ridner et al. (2011)'s study, 20% of the participants living with lymphoedema did not believe that they were able to improve their symptoms by self-management. **External** motivation was described by PLWL as self-management perceived as instructions that needed to be followed, people with such external motives described finding these difficult to sustain in the long-term, even if they tried them for a while (Jeffs et al., 2016, Fu, 2010). **Introjected** motivation was described as the start of internalising the behaviour, which usually showed itself as a sense of guilt. PLWL expressed feeling faulty and bad about not self-managing (Fu, 2010, Greenslade

and House, 2006). **Identified** motivation was related to behaviours that correlated with personal goals and values. PLWL who previously experienced severe lymphoedema symptoms described not having such consequences again as their main motivation for self-management (Bogan et al., 2007). **Integrated** motivation was perceiving self-management as an integral part of life, which was supported through confidence and sustained routines in lymphoedema (Barlow et al., 2014a, Bogan et al., 2007, Fu, 2010).

This perspective implies that telling and nudging people about what needs to be done to manage lymphoedema may not be an effective strategy, and a shift towards supporting individuals to develop autonomy is needed. Bisset and Lockton (2010) discussed that the role of design needed to go beyond providing motivation, but to empower individuals to be motivated by themselves. Ryan and Deci (2000)'s Self-Determination theory sets autonomy as a fundamental human need, besides competence and relatedness. Hence, highlights motivation in relation to other human needs including social, intellectual and physical elements that drive behaviour.

2.3.5 Self-Management as Self-Efficacy and Social Learning

Self-efficacy has been described as the belief of an individual about their capacity to achieve a desired performance (Bandura, 1977). According to Bandura (2004) if someone believes that they could improve their health they would be more likely to put effort in doing so by changing their health behaviour. In lymphoedema, some individuals described their confidence in being able to manage their condition, while some others expressed feeling out of control: "*Lymphoedema seemed to be something like an incoming tide; ... there didn't seem to be anything you could do about it*" (Meiklejohn et al., 2013).

According to Bandura (1977) perceived self-efficacy was influenced from the following four main factors:

- 1) *Performance Accomplishments: when we experience success, we believe we can be successful again.*
- 2) *Vicarious Experience: when we see others success, we may believe that we can also be successful.*
- 3) *Verbal Persuasion: when someone tells us that we can `succeed`, our belief in being successful might increase.*
- 4) *Emotional Arousal: when we are not feeling anxious or worried we are more likely to believe in being successful (Bandura, 1977).*

As shown in Figure 2-9 self-efficacy was influential for health behaviour both directly and also indirectly by influencing outcome expectations, goals and socio-structural facilitators and barriers (Bandura, 2004).

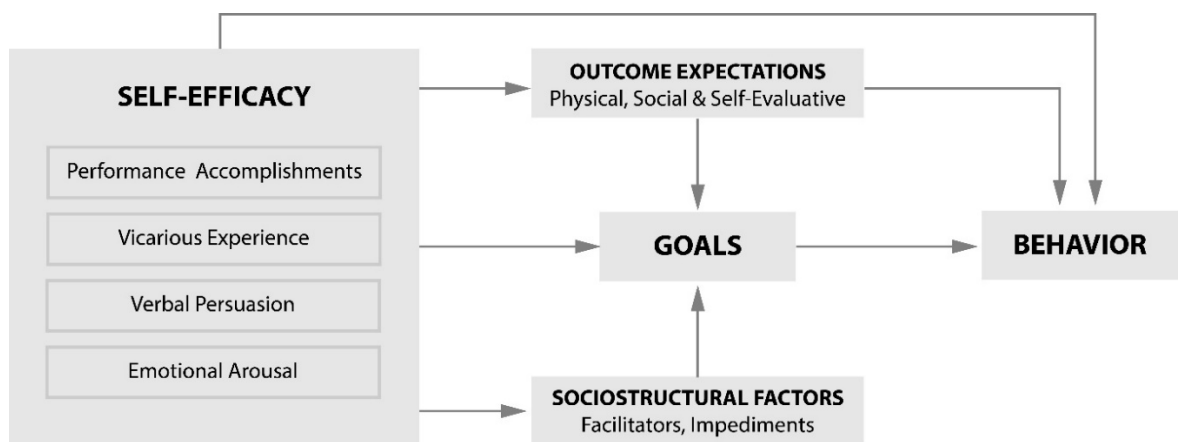


Figure 2-9 Social Learning Theory adapted from Bandura (1977) and Bandura (2004)

Bandura's Social Learning Theory highlights the influence of internal and external social determinants on health behaviour. For design, this perspective to self-management implies the importance of the social influence in promoting the self-efficacy of individuals. This could include sharing success stories and facilitating reassurance in being able to manage lymphoedema. Another concept introduced by Bandura (2019) was '**Guided Mastery**' in which individual was supported to develop the required self-efficacy for a

particular behaviour change. During this psychological treatment originally developed for people with snake phobia, the support would gradually be changed and increased until the desired behaviour was achieved (Bandura, 2019). For design, this perspective implies a gradual change in the provided support to match the needs of the individual.

2.3.6 Self-Management as Acceptance

The voices of PLWL as described in the literature demonstrate the strong emotional reactions and psychological impact of the diagnosis on individuals. Kübler-Ross and Kessler (2005)'s five-stage theory has described the emotional adaptations individuals go through during negative life changing events. Their theory was originally built for explaining the grief of terminally ill individuals and was later generalised to include emotional reactions to chronic disease diagnosis (Kübler-Ross and Kessler, 2005). As shown in Figure 2-10, to survive the loss, or the news of a chronic condition requiring rigorous self-management, people start with denial of the event. Once one starts to accept the news and starts questioning the occurrence, the previously denied emotions such as anger and depression can start to show. According to Kübler-Ross and Kessler (2005) these are all parts of the acceptance process. However, acceptance of the new and permanent reality does not always mean they are `all right` about it.

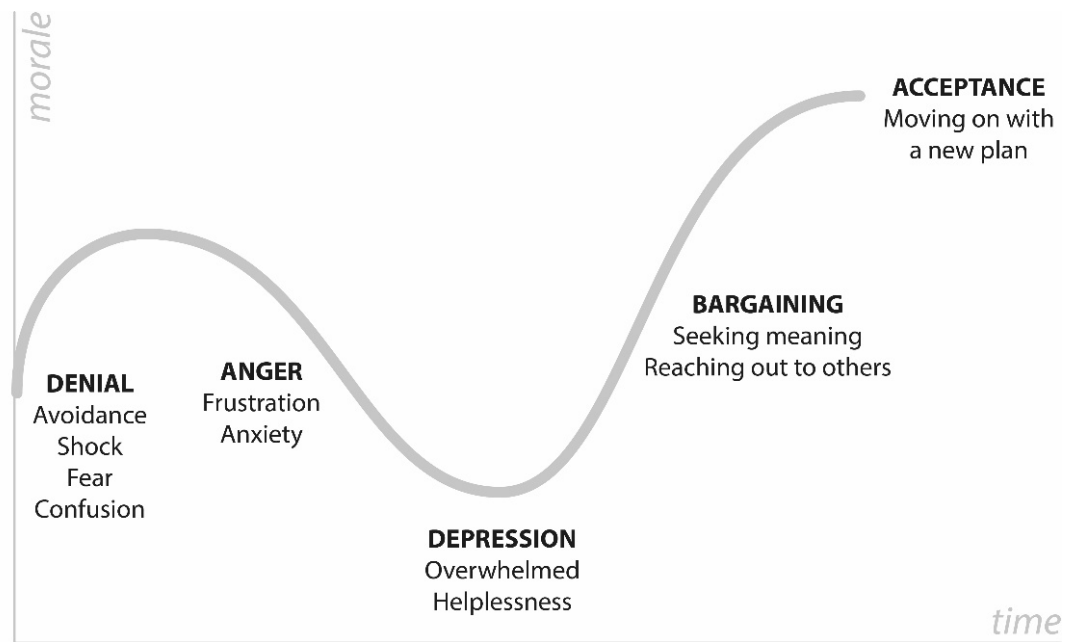


Figure 2-10 The Five Stages of Grief Model adapted from Kübler-Ross and Kessler (2005)

PLWL described their emotions after their lymphoedema diagnosis from denial and anger to acceptance. The following quotes from PLWL exemplify such emotions: *“I kept thinking somebody’s going to re-diagnose me and I haven’t really got lymphoedema”* (Meiklejohn et al., 2013), *“I can’t do anything anymore! I am so depressed! Nothing is the same in my house! This thing overpowers everything!”* (Maree and Beckmann, 2016), *“It’s something I know I have to live with and deal with and I’ve accepted that”* (Bogan et al., 2007).

The Stages of Grief Model demonstrates emotions people might go through while coming to terms with living with a chronic condition. For design, acknowledging the possibility of such reactions to diagnosis will allow the system to better match the support to the needs of the user at particular stages.

2.3.7 Self-Management as Biographical Disruption

A narrow medicalized view of suffering, solely defined as physical discomfort, ignores or minimizes the broader significance of the suffering experienced by debilitated chronically ill adults. A fundamental form of that suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued new ones (Charmaz, 1983)

As discussed by Bandura (2004) the experience of living with a chronic condition is not only a personal matter, but also a social one. PLWL as described in the literature expressed their worries about the limitations their condition posed to their social identity and lives, feeling isolated and being a burden to their loved ones (Bogan et al., 2007, Fu, 2010, Fu and Rosedale, 2009, Meiklejohn et al., 2013). These remarks of PLWL align with Charmaz (1983)'s descriptions of 'loss of self' in chronic conditions. Goffman (1959) in their Presentation of Self, described how individuals are willing to be perceived by others as their 'ideal' versions, and chronic condition experience was disrupting this 'ideal' (Bury, 1982). Self-management of a chronic condition usually requires change in lifestyle and limitations to everyday life, which may be part of how individuals define themselves in the society. Bury (1982) has distinguished three aspects of this 'biographical disruption' introduced by a chronic condition: 1) "*disruption of the taken-for-granted assumptions*", 2) "*rethinking of the person's biography and self-concept*" and 3) mobilising resources as a response to the disruption. These were shown in Figure 2-11.

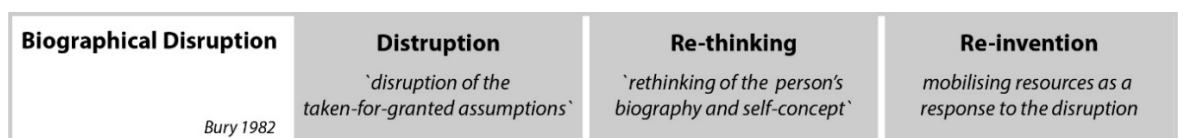


Figure 2-11 Biographical Disruption adapted from Bury (1982)

This sociological perspective to consider self-management as a 'biographical disruption' implies understanding some of the underpinning social constructs of the

barriers against self-management. Individuals want to keep living as their `ideal` selves, who can continue to participate in society as `able-bodies`, and free from the limitations of their chronic condition and the chores of the everyday self-management. For design, this perspective implies supporting individuals to re-construct another `ideal`, who is living a cherished life with a chronic condition. As one of the ways to “*give voice to the body*” and support re-construction of the identity, encouraging people to share their stories with their condition has been suggested (Frank, 2004).

2.3.8 Self-Management as Patient Activation

The collaborative care approach to self-management is centred on people’s active engagement in their healthcare (see section 2.2). It has been shown that an increase in patient activation results in enhanced self-management behaviour (Hibbard et al., 2007). Though, *were patients ready to be active in their self-management? If not, to become `activated` what would they need?* Hibbard et al. (2004) has presented a measure to assess patients’ activation in their chronic condition care. The Patient Activation Model takes into consideration the skills, knowledge and behaviours needed by a patient to be active in their self-management (Hibbard et al., 2004). According to Hibbard and Gilburt (2014) there are four levels to patient activation as shown in Figure 2-12.

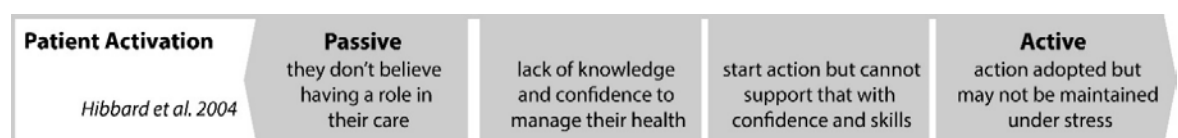


Figure 2-12 Patient Activation Model adapted from Hibbard et al. (2004) and Hibbard & Gilburt (2014)

At the **passive** level, individuals do not believe they have a role in their care. Lymphoedema self-management did not match the expectations of some individuals, and

they described a desire to stay passive in their care and being taken care off: *“I imagined getting a treatment... where I could lie on the bed and get treated and then go home”*

(Karlsson et al., 2015). Despite being essential, understanding their role in self-management is not enough alone for patients to become active in their care (Hibbard and Gilbert, 2014). That requires acquiring knowledge and confidence in self-management. PLWL described many barriers that hindered their knowledge and confidence, despite their desire to be active in their self-management (Barlow et al., 2014a, Deng and Murphy, 2016). At the **active** stage, individuals practice the new behaviours needed for their care. Yet, that may not be necessarily maintained during major life events or when under stress (Hibbard et al., 2004). PLWL described proactively managing their condition and the cases where they even had to `remind medical professionals` about their lymphoedema (Ridner et al., 2016).

The patient activation model has demonstrated the stages towards being active in one's healthcare. For design, this approach implies that people can be at different levels in terms of how active they are in their healthcare. This model considers the skills, knowledge and behaviours necessary to facilitate patients to be active in their self-management.

2.3.9 Self-Management as Patient Engagement

The concept of engagement implies the patients' personal choice to change their attitude toward the health care system, from passive, to a partner and co-pilot with the health provider of the health care journey. (Graffigna and Barelo, 2018)

Increased patient engagement has been discussed to have a positive influence on self-management. It is described as having understanding, knowledge, confidence and skills to self-manage (Simmons et al., 2014). Graffigna et al. (2015) have suggested that previous models such as Patient Activation are primarily focused only on the behavioural aspects of patient experience and overlook the psychological component. Their Patient

Health Engagement Model points to the role of emotions as the main driver of individuals' engagement in their healthcare and is inspired from the Kübler-Ross and Kessler (2005)'s emotional adaptation model (section 2.3.6) and Prochaska and DiClemente (1983)'s model of change (section 2.3.3) (Graffigna and Barelo, 2018). As shown in Figure 2-13 they define four stages considering the thoughts, feelings and behaviours of people living chronic conditions (Graffigna and Barelo, 2018).

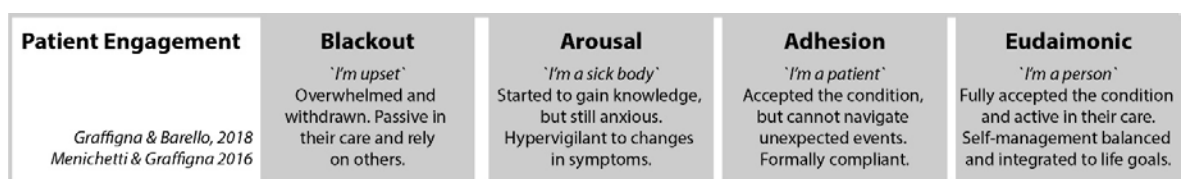


Figure 2-13 Patient Engagement Model adapted from Graffigna and Barelo (2018) and Menichetti and Graffigna (2016)

People's emotions about their condition and their acceptance process are taken into consideration in the Patient Engagement Model. These were not included in the Patient Activation model (section 2.3.8). Moreover, the Patient Engagement Model is not only interpreted as a survey for understanding the stage of the individual, but also for defining interventions for these different levels of health engagement (Menichetti and Graffigna, 2016). These interventions consist of face-to-face sessions with trained facilitators that focus exercises on emotional adjustment, health behaviour change and health information seeking (Menichetti and Graffigna, 2016). For design, this approach implies tailoring the system to change the provided support depending on the engagement level of the users. This model considers the emotions, thoughts and behaviours necessary for engaged self-management.

2.3.10 Summary

Nine theoretical perspectives to self-management have been described above. These allow understanding the phenomenon from multiple point-of-views. Yet, none of these models are fully representative to describe the lymphoedema self-management experience by itself alone, as shown by the analysis done in this thesis. Lymphoedema self-management experience involves psychological, behavioural, motivational and social factors. Hence, this theoretical literature review was widened on the foundation presented in this section. A systematic selection of the literature describing lymphoedema self-management experience was conducted, and these were thematically analysed and synthesised in relation to these grounded theoretical models. The results of this secondary research is presented in Chapter 4 of this thesis.

2.4 Design for Health and Wellbeing

The key is to shift our focus from helping people to fit our care delivery system, to one where we design our care delivery system to fit people where they live, work, learn, play, and receive healthcare... We believe that delivery science that is supported by design methods holds the key to redesigning healthcare to meet people's requirements (Erwin and Krishnan, 2016)

Design research has been recognised as having strong potential to navigate in the complex landscape of health and wellbeing (Chamberlain and Craig, 2017a, Tseklevs and Cooper, 2017, Bazzano et al., 2017). Traditionally design in healthcare was limited to the design of medical devices, spaces or graphical communications. More recently, a broader potential for value by design has been recognised, where the value of design is not only to the immediate users or products, but also to society, economy, culture and environment by creating positive change (Rodgers et al., 2020). Design has started to be considered as a way to strategically create value, to investigate not only people's needs, but also what is

meaningful for them and why (Van der Bijl-Brouwer and Dorst, 2017). Human-Centred Design (HCD), which considers the involvement of potential users and other stakeholders at the centre of the design process, has been a fundamental quality of design. Previously, the value of HCD approaches within health and wellbeing context has been exemplified (Kanstrup, 2014, Balaam et al., 2011, Bate and Robert, 2006, Pickles et al., 2008, McCarthy et al., 2016, Chamberlain and Partridge, 2017, Rodgers, 2020).

Engaging with HCD by involving people/users/patients/stakeholders actively to the design process from the early front-end of the process, is generally considered important to maximise the creation of value in design (Koen et al., 2002, Kim and Wilemon, 2002, Sanders and Stappers, 2012). Even though there are many variations to the design process, the characteristics of the front-end of these processes have some commonalities. Two frequently cited design processes are shown in Figure 2-14. The Double Diamond model, which was introduced by the Design Council, consists of two diamonds/sections. One of the diamonds represent the front-end which relates to the discovery of the challenge and one back-end about the development of the outcome (Council, 2019). The Double Diamond visualises and differentiates the divergent (creative generation of options) and convergent (analytical evaluation of the options) thinking processes. In this model the front-end implies the critical discovery of the `challenge` by divergent thinking to ensure setting a meaningful `design brief`. The other well-known description of the design process is by Sanders and Stappers (2008) which highlights less structured iterations with the generation of certain outputs along the way and as a co-design process with involved stakeholders throughout. The front-end of design process includes decisions about what will be designed (whether it is a product, service or system), what it will do (function) and why (aim). Sanders and Stappers (2008) describes this front-end as `fuzzy`. This stage is

for setting the question/problem/brief with the involvement of the users. The aim is to ensure that the right question is investigated and solved.

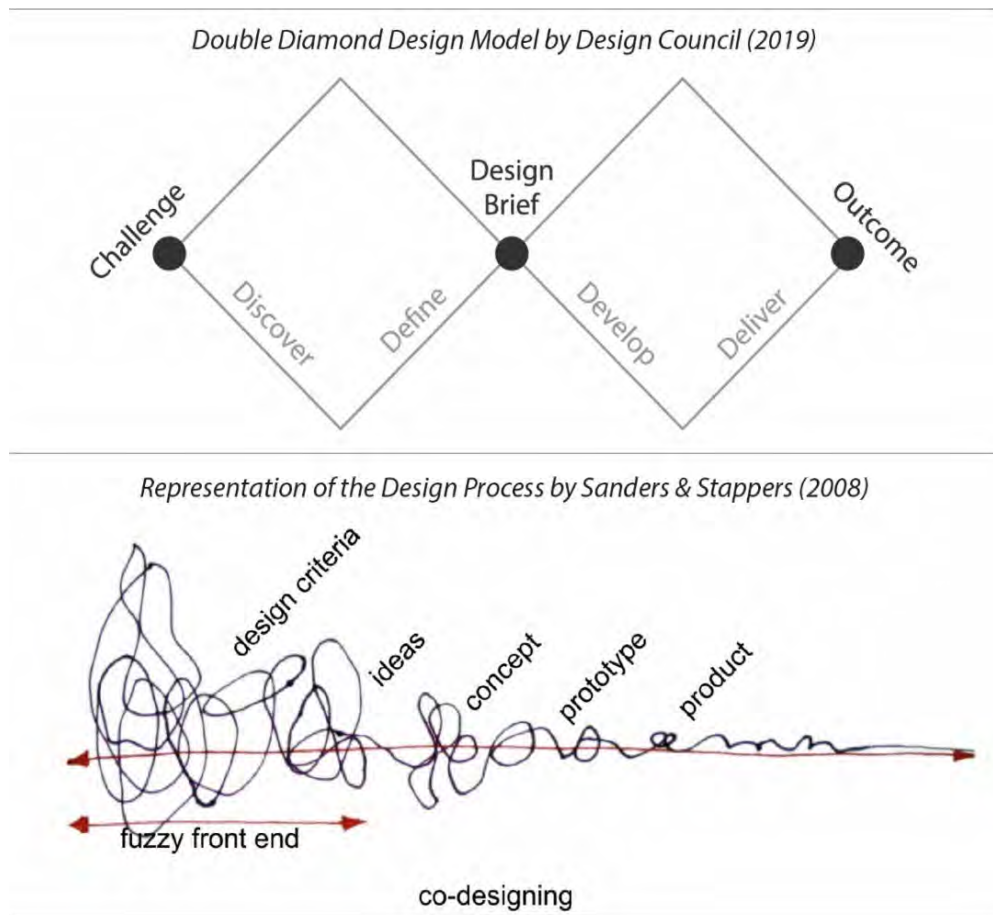


Figure 2-14 Design Models: Above Double Diamond by Design Council (Council, 2019), Below representation of the Design Process (Sanders and Stappers, 2008).

The front-end design decisions are critical for maximising the value for users and opportunities for innovation (Koen et al., 2002, Kim and Wilemon, 2002). However especially in healthcare, user feedback is commonly sought for the evaluation of systems at the back-end of the design processes. As McNichol (2012) asserted, the front-end decisions such as research agendas or system functions were usually defined without patient input. Schaeffer (2012) described this approach as `prevention through design` which fundamentally aims to improve the safety, effectiveness and user satisfaction of a design with functions and forms that are previously defined, and not always with the involvement

of end-users. Such late involvement of end-users and patients, restricts their contribution to the design, since changing directions at later stages is usually not possible (McNichol, 2012). There are some prevalent methods practiced in healthcare at the front-end of the design process, such as questionnaires targeted at patients, carers and experts to identify unmet needs (Moody, 2015). However, the depth of response is limited when participants are directly asked what is needed, and not all needs can be explicitly articulated following such methods (Sanders and Stappers, 2012, Chamberlain, 2010). Sanders and Stappers (2012) suggested deeper engagement with expected users to explore their latent and tacit needs.

Design for health and wellbeing is inherently multidisciplinary. Despite the agreement on the value of HCD within healthcare, challenges were also recognised that were intrinsic to the collaboration between the design research and health sciences. Melles et al. (2021) discussed the differences between the mainstream research methodologies for these professions. Quantitative analysis of clinical trials with large sample sizes are valued in medical disciplines. While HCD favours in-depth qualitative user studies in small sample sizes. Hence, it was argued that HCD could be perceived as not providing the necessitated evidence-base results by professionals in healthcare (Melles et al., 2021, Bazzano et al., 2017). The expectations from research outputs were also discussed to be different. Usually the design of a product or service could be considered as a research output in design research by itself, while for health sciences the quantified impact of that design could be the only publishable research output (Bazzano et al., 2017). Better understanding of the methods and outcomes between these fields of studies is needed and could potentially create further opportunities to collaborate for improving health and wellbeing.

Previously there was also a criticism on design studies which focus on pushing technology without fully understanding the everyday experiences of patients (Dunn et al., 2019, Nunes et al., 2015). Kanstrup (2014) described that in design studies, the primary focus was on the body with the chronic condition and the medical management side, while little attention was posed on the everyday self-management experience of people. According to Kanstrup (2014) that could have been either because every day experiences were undervalued or it was too difficult to design for such a broad space. Nunes et al. (2015) discussed that HCD should further focus on real everyday lives of patients and better utilise the related interdisciplinary literature, to provide solutions to the right issues. As discussed by McNichol (2012), ‘patients are experts in living with their own condition’ and their expertise should be influential in front-end design decisions. Wildevuur and Simonse (2015) reviewed 350 systems that were designed for people living with chronic conditions. They concluded that none of these systems were able to ‘fully’ facilitate a person-centred care, which encourages a partnership between the healthcare providers and patients, and their shared decision-making (Wildevuur and Simonse, 2015).

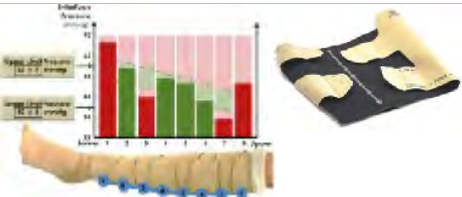


Design research aspires to create value and meaningful solutions for people’s health and well-being. However, if the real everyday experiences of people living with chronic conditions are not understood, there is a risk of answering the wrong questions by design and pushing technology. Human-centred design methods have potential to bring opportunities for better design of the self-management support systems at the fuzzy front-end. Yet, available theories and literature on the experience of people living with chronic conditions is not portrayed in a way that is applicable for design purposes, and how such real-world experiences of users could inform design is not fully investigated.


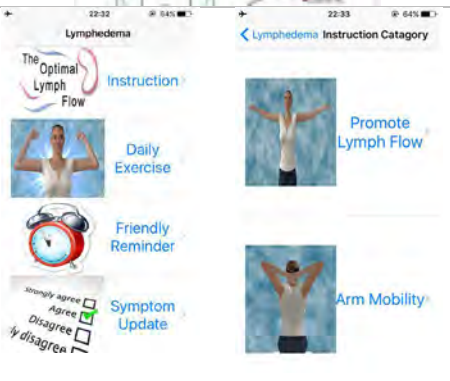
2.5 Available Support Systems and Assistive Technologies for PLWL

The products developed for the management of lymphoedema were investigated through a review of the literature. These are shown in Table 2-3 and are categorised according to their intended functions and users.

Table 2-3 Support Systems and Assistive Technologies for PLWL – Market Research

Function and User	Product Name and Reference	Visuals
Testing Compression Garments: Used by the compression garment testing facilities to test the pressure of the compression garments	The hatra hose pressure tester (SMTL, 2009)	
Clinical Pressure Monitoring: Used during the intensive therapy by the lymphoedema therapists. The aim is to measure the interface pressure between the compression garment and the skin to achieve a better bandaging performance and compression garment fit.	Kikuhime tester (Meditrade, Soro, Denmark), Oxford Pressure Monitor, The Talley Skin Evaluator, The PicoPress (Microlab, Padua, Italy), Tekscan I-scan and Tekscan FlexiForce, Smart mannequin system: (Wang et al. 2011), Simulated Wear and Tear (with Tekscan) (Brorson et al. 2012) Evaluating the Kikuhime pressure monitor: (Brophy-Williams et al., 2014)	
	Kikuhime Telecare (McLaren et al., 2010)	

Self-Monitoring: Intended to be used by lymphoedema therapists and by PLWL during self-management to provide feedback about the applied pressure and the progress of the swelling.	Flexible iontronic sensing assay: (Li et al., 2016)	
	Pressure-sensitive microfluidic film: (Nie et al., 2015)	
	Ankle circumference / smart cuff (Fallahzadeh et al., 2015)	
Active Compression Devices: Intended to be used by PLWL as a part of their self-management to increase the lymphatic flow.	Pneumatic Compression Pumps for Management of Lymphedema (OlszewskiWaldemar, 2014, Alvarez et al., 2012)	
	Active Compression Brace actuated by Shape Memory Alloys (Moein et al., 2017)	
Sleeves to be worn by PLWL over their medical compression garments for improving the aesthetic of compression garments.	Tattoo Arm Sleeve (Ercolano, 2012)	
Tele-Consultation: Intended to be used by PLWL and their therapists	Tele-Consultation for Self-Management of Chronic Lower Limb Swelling: (Faett et al., 2013)	

to facilitate remote consultations.	e-CUIDATE “ <i>measuring the participant's arm circumferences via a telehealth application</i> ” (Galiano-Castillo et al., 2013)	
Digital Applications to Support self-management: Intended to be used by PLWL to support their daily self-management.	The-Optimal-Lymph-Flow health IT system (TOLF) information and exercise guide (Fu et al., 2016a, Fu et al., 2022)	

Among the investigated products, one of the areas of focus was the assessment of the actual pressure applied to the user by the compression garment. Thomas and Morgan (2017) have asserted that some commonly used compression garments are found to be incorrect when tested. They highlighted the importance of assessing compression garments prior to their inclusion to the formulary (list of garments that could be prescribed to patients) (Thomas and Morgan, 2017). External testing facilities were conducting these assessments and reporting back to the lymphoedema professionals (SMTL, 2009). There were also products in the market designed to be used by lymphoedema professionals in clinics to measure the interface pressure between the compression garment and the skin (ie. Kikuhime tester, The PicoPress, Tekscan I-scan and Tekscan FlexiForce see Table 2.1). Such devices were intended to be used to ensure graduated compression was achieved during intensive bandaging, besides allowing the therapist to test the pressure levels of the fitted compression garments. There were also research studies for the development of pressure sensors that could be worn so that the user with lymphoedema and their therapists

can monitor these dynamic pressure levels during the day (Li et al., 2016, Nie et al., 2015, Fallahzadeh et al., 2015, McLaren et al., 2010).

Another group of products were the ones providing intermittent pressure to their users. Pneumatic compression pumps were available for purchase by PLWL. Research studies evidenced that these pumps were helpful to soften the tissues and were beneficial for lymphoedema management (OlszewskiWaldemar, 2014, Alvarez et al., 2012). These pumps require the user to stay in seated position and wait for the duration of the treatment. There were some research studies to develop versions that could be worn by the user while they continue their regular activities (Moein et al., 2017).

Compression garments are deemed essential for lymphoedema management. However, PLWL described the look of these garments as negatively influencing their confidence and lymphoedema experience (Lam et al., 2006). Apart from some additional colour options, the look of compression garments has not evolved in the same way as fashion trends did over the years. A sleeve that could be worn on top of compression garments were designed to allow users to select the patterns and colours they would like to wear (Ercolano, 2012).

Another area of focus was Tele-Consultation aiming to enable remote communication of PLWL with their therapists. The main challenge in teleconsultation for lymphoedema management was perceived to be taking measurements for the assessments and garment fitting (Galiano-Castillo et al., 2013). A digital application called e-CUIDATE included sections for PLWL to note down their circumferential limb measurements and shared these with their therapists besides providing exercise programs (Galiano-Castillo et al., 2013). A randomized controlled trial with PLWL were conducted to validate the effectiveness of e-CUIDATE and showed improved symptoms (Galiano-Castillo et al., 2016). Another digital application was called The-Optimal-Lymph-Flow

(TOLF), and focused on providing guidance for exercises and setting reminders for self-management activities (Fu et al., 2016a). The usability of the TOLF application was tested and received positive responses from PLWL (Fu et al., 2016b). However, in terms of their development approach, none of these products mentioned an engagement with the end-users during their design processes.

An international consortium project was funded by Ageing Well in Digital World scheme in 2012 for the development of a smart compression garment. The study was not directly on lymphoedema management, but it was for the development of a product that could potentially be used by PLWL. The group reported the results of the initial feedback sessions conducted with the users and healthcare professionals, however the study was not completed (Christensen, 2015). The literature review did not find evidence of any other human-centred product development projects related to lymphoedema self-management.

Nevertheless, for the management of other chronic conditions many supportive systems and assistive technologies existed. Reviews presented that these were perceived useful, and typically involved behaviour change interventions of self-monitoring, goal-setting and social support (Phillips et al., 2018, Mercer et al., 2016). However, these technologies were usually complemented with external incentives and coaching, and there was limited evidence on the ability of such technologies to sustain behaviour change alone (Phillips et al., 2018, Marcolino et al., 2018). A review on mobile health technologies discussed that meaningful involvement of patients in the design process was one of the key challenges in this area (Voorheis et al., 2022).

Products for supporting lymphoedema self-management were scarce, and little evidence was found in terms of the involvement of PLWL in the development of these existing systems.

2.6 Summary

In this literature review chapter:

- Lymphoedema as a medical chronic condition and its self-management is introduced.
The transition from intensive therapy to self-management is identified as a stage where PLWL seek further support. In this PhD study, focus is determined to be for supporting the self-management of PLWL.
- Traditional and collaborative care approaches to chronic condition management are introduced. In this study, a collaborative human-centred care approach is taken and PLWL are considered as the `experts of their own condition`. In this thesis, instead of traditional health outcomes, the `empowerment` of PLWL is regarded as the focus.
- A gap in the literature about utilising multidisciplinary theoretical groundings about self-management for the design of assistive technologies is identified. 9 theoretical models related to self-management experience are introduced and their potential implications for design are discussed. In this study, the relation of these theoretical groundings with the lymphoedema experience is investigated further and built the foundation of the proposed model.
- Design in health and well-being and HCD are introduced. The value and importance of investigating the lived chronic condition experience at the front-end of design process is discussed. In this thesis, the fuzzy front-end of chronic condition self-management is investigated following a HCD approach.
- Available products to support lymphoedema self-management are presented. In this context, a gap in human-centred product development is identified.

As a response to the identified gaps in the literature, the focus in this study is on the front-end HCD research for supporting PLWL in their self-management. The lived

everyday experiences of individuals are prioritised and a collaborative human-centred approach to wellbeing is endeavoured. Multidisciplinary theoretical groundings related to the everyday self-management experience are investigated. Hence, the main research question of this thesis is:

How might we design to support the empowerment of PLWL in their self-management?

The following chapter presents the research approach and the methods followed in this study.

Chapter 3 Methodology

In this chapter, the methodology and research approach are explained. The chapter starts by explaining the design research approach undertaken. Then, the particular methods adopted and the selection of the participants for the studies are described. Finally, the ethical considerations and the limitations of the methodology are explained.

3.1 Design Research Approach

A design research approach was adopted. The research question inquired in this study had three main characteristics:

- 1) Future Oriented:** The question investigated future possibilities and the ways design might create value, particularly to support the empowerment of PLWL.
- 2) Iterative and Reflective:** The answer to the question was unknown and could not be hypothesised in advance. Its inquiry required iterative reflection on the practice.
- 3) Collaborative and Empowering:** Answering the question necessitated collaboration with and the participation of PLWL, who were experts in their own experience, and the healthcare professionals.

3.1.1 Future Oriented

This PhD study looked into a `future` where the empowerment of people living with a chronic condition is supported. Design research has been widely characterised as future oriented. Cross (1982) distinguished design research and `designerly ways of knowing` from traditional fields of science and humanities, and described design as

constructive, solution-focused and future oriented. Gaver (2012) emphasised the generative nature of design in creating “*what might be*” which was “*provisional, contingent and aspirational*”, instead of being verifiable, extensible and falsifiable scientific statements. Design research not only explores how things and experiences were at a certain time, but also creates a leap to future to explore “*how the future ought to be*” (Rodgers and Milton, 2013). Design probes (Gaver et al., 2004, Mattelmäki, 2006) and designed critical artefacts have been used to allow such future facing insights with the engagement of the stakeholders in design research by “*suspending the user between reality and fiction*” (Chamberlain and Craig, 2017b).

According to Dorst (2011) the future-oriented design approach results from a unique way of reasoning. Dorst (2011) referred to Charles Peirce’s fundamental reasoning methods (deductive, inductive and abductive reasoning) to explain the reasoning in design. Table 3-1 presents deductive, inductive, abductive 1 and abductive 2 reasoning with descriptions and examples.

Deductive reasoning is for exploring results of a known phenomenon, so as long as the leading facts are true the result can be expected to be true. Hence, inquiry of ‘what’ and ‘how’ leads to a result. **Inductive reasoning** is for exploring how a phenomenon creates results, so premises are utilised to create untested results. Hence, the ‘result’ and ‘what led to that result’ will allow us to estimate how a phenomenon could be in the future, relying on extrapolation of past occurrences.

Differing from deductive and inductive reasoning, which are used for justification and discovery of a phenomenon, design focuses on creating ‘value’. **Abductive reasoning** takes a leap into the future to create space for generating new products and ideas. Dorst (2011) described two versions of abductive reasoning: **Abduction 1 (Explanatory Abduction)**, which is a common reasoning method in problem-solving, focuses on ‘what’

(a product or service) can create the desired `value` within known principles (Dorst, 2011, Roozenburg, 1993). Abduction 1 is the approach used to generate design briefs in industrial practice, in which the working principle of a product, design requirements and the desired value are defined. Shifting focus of design from the artefact (what) to a `purpose` has brought about the “**Abduction 2 (Innovative Abduction)**” approach which is an “*open form of reasoning*” (Dorst, 2011). Abduction 2 has emerged in parallel with new design fields and approaches such as design for wellbeing and design for sustainability. In Abduction 2, the “*working principle*” is simultaneously explored with the artefacts for creating a value (Table 3-1).

In the abductive reasoning approach, imagination is used to explore how the future might be improved. Dorst (2011) set Abduction 2 as the core of reasoning in design thinking and for conceptual generative design. Sanders (2005) described generative design as the research conducted at the front-end of the design process to generate new ideas and opportunities for design. Abduction 2 is used at the front-end of the design process which involves making decisions on `what` will be designed (Is it a product, service or system? What are the functions and requirements?) and `how` it will function.

This research study is an example of abductive reasoning conducted at the-front-end of the design process. The main research question of this study was: How might we design to support the empowerment of PLWL in their self-management? Referring to the reasoning principles of Abduction 2, only the aimed value was defined (the empowerment of PLWL in their self-management). This study explored the ways design might assist achieving that value. The research focused on exploring both `what` and `how` elements. This study not only explored how the current situation was, but also how it might be improved. New knowledge was gained from exploring alternative futures for the mentioned domain.

Table 3-1 Deductive, Inductive and Abductive Reasoning: Adapted from (Dorst, 2011)

DEDUCTION	<p>What + How = ? (Result)</p> <p>Observe/experiment the phenomenon in relation to the theory</p> <p><i>Example: What is the prevalence rate of Lymphoedema in Wales? Wales has a population of around 3.168 million people and there were approximately 17000 lymphoedema patients in Wales in 2017. Result: the prevalence rate of Lymphoedema in Wales in 2017 is about 5.49 per 1000 (Thomas and Morgan, 2017).</i></p>
INDUCTION	<p>What + ? (How) = Result</p> <p>Generalise observations and experiments to build theory</p> <p><i>Example: Among breast cancer survivors, how many survivors would be expected to develop lymphoedema? A meta-analysis exploring the incidence of unilateral arm lymphoedema after breast cancer, showed a range between 8.4% and 21.4% by the data abstracted from 72 studies of 29 612 women with breast cancer. Result: probably one in every five women who survive breast cancer will develop arm lymphoedema (DiSipio et al., 2013).</i></p>
ABDUCTION 1	<p>? (What / product or service) + How = Value</p> <p>Create space to generate new products or services</p> <p><i>Example: Decongestive lymphatic massage is known to be helpful to manage lymphoedema. The design of a pneumatic compression pump that simulates a decongestive lymphatic massage would require application of Abduction 1 reasoning. That would be an exploration of a product with defined working principles and aiming to achieve a value.</i></p>
ABDUCTION 2	<p>? (What / product or service) + ? (How / the working principle) = Value</p> <p>Create space to generate new ideas and knowledge</p> <p><i>The main research question of this study is an example of Abduction 2 reasoning: How might we design to support the empowerment of PLWL in their self-management? Referring to the reasoning principles of Abduction 2, only the aimed value is defined - the “empowerment of PLWL in their self-management”.</i></p>

3.1.2 Iterative and Reflective

The boundaries of design research and its links to design practice have been an ongoing discourse. Initially, design research was a process of inquiry about design only. It was not considered to produce new knowledge beyond design methods, theory and history.

Frayling (1993) referred to experimental science, to discuss the unique opportunities practice-based design can bring to design research. A wider scope and three distinct categories were defined by Frayling (1993) and Archer (1995) namely: `research **into** design`, `research **for** design` and `research **through** design`.

- **Research into design** focuses on design as its subject without engaging with it; studies about design history, theories, processes and methods are considered in this category.
- **Research for** the purposes of **design**, provides knowledge about a subject for the practice of design, to design a better product or service.
- **Research through design (RtD)**, inquiries knowledge about a subject (which goes beyond design) by the practice of design.

RtD explores knowledge through the practice of design and iteratively reflects on the outcomes. Yet, the focus of RtD is on the process rather than the final output `the design`, Lambert and Speed (2017) emphasised that “*“the doing` (the process) yielded more new knowledge and insight than `the done` (the outcome)”*. Chamberlain (2010) highlighted the `tacit` knowledge that can be gained by the design process and the critical artefacts created as a result. In RtD, the subject domain is transformed by design. That transformation brings opportunities to gain knowledge, otherwise not accessible, by presenting insights about alternative futures (Archer, 1995, Storni, 2015, Zimmerman and Forlizzi, 2008, Rodgers and Milton, 2013).

RtD and `Action Research` have commonalities; both are iterative and active practices of changing a system and gaining knowledge from observing and reflecting on the influence of that change (Archer, 1995, Swann, 2002, Silverman, 2015). Lewin (1946) developed the action research methodology to address critical social problems. He argued that traditional positivist research was not appropriate for such issues and proposed action

research as a democratic and collaborative methodology to bring transformative change to solve problems and learn from this transformation. In action research, knowledge is acquired by solving problems and creating change, and reflecting on the results of this change. Action research has commonly been described as 'spiral of steps', involving the planning of the action, the implementation of the action, observing the results of the action and reflecting on these in an iterative manner (Lewin, 1946, Bradbury, 2015). In action research, the researcher takes action according to the current understanding on the situation, without being able to predict how that action will be perceived. The action is re-examined iteratively with the involved stakeholders repeating the cyclic steps: plan, implement, observe and reflect (Figure 3-1),

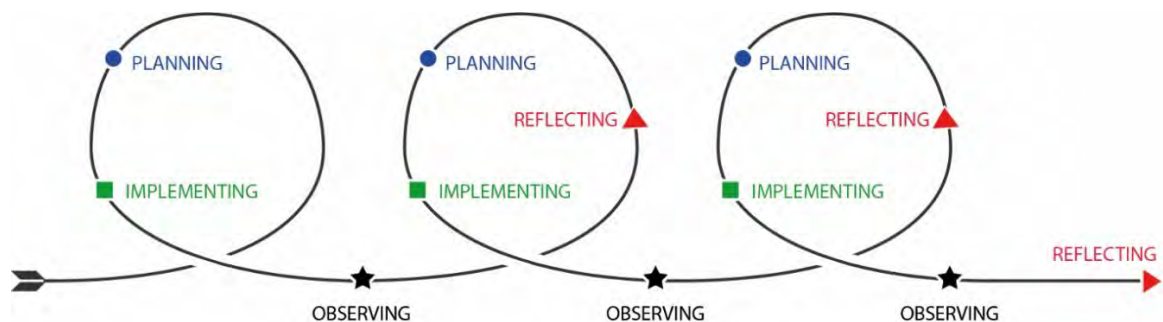


Figure 3-1 Steps of action research: Planning, implementing, observing and reflecting

This PhD study followed a reflective design practice approach in an iterative manner as shown in Figure 3-2. The cycle started by gaining an understanding of the current situation and planning the study according to these reflections. The planning phase involved the development of the design probes, which were projections of how the future of self-management might be. Insights were gained from the development of these design probes and participants' interactions with them. The research process was iterative; the results of each study affected the planning of the following research method. While the

research informed the development of the probes, these design probes informed the research in a reflective manner.

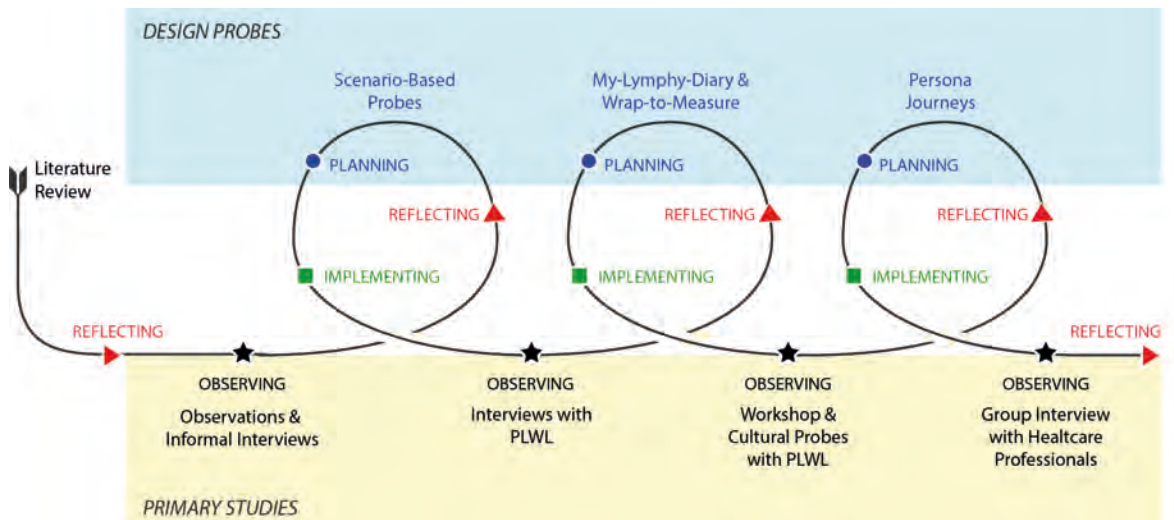


Figure 3-2 Iterative and reflective design process followed in this PhD

The iterative cycles shown in Figure 3-2 were conducted in collaboration with PLWL and their healthcare providers. Hence, the third characteristic of the research approach of this PhD study was being collaborative and empowering.

3.1.3 Collaborative and Empowering

The involvement of PLWL and their healthcare providers was fundamental for this PhD study. Previously in the design research literature, recognising the involved people as experts in their own experience and collaborating with them during the whole design process was agreed to ensure better fit to their needs and deeper insights about their experience (Sanders and Stappers, 2012, Rodgers and Milton, 2013). Collaboration allows the voices of the stakeholders to be heard and aims to develop a change that is democratic. In this way, knowledge is gained not only from the designer's own reflective practice, but also from the collective practice of the other people involved. Such collaborative design methods have been proposed to 'empower' the participants by creating a platform for them

to (co)-design (Winton and Rodgers, 2019, Uzor et al., 2012, Chamberlain and Partridge, 2017). For instance, Winton and Rodgers (2019) organised co-design studies with people living with dementia; they reported benefits to the participants including increased esteem and social connection. Hence, in their design research `empowering` was not only implied as a characteristic of the design output, but also as a characteristic of the collaborative design process. Drain et al. (2021) proposed that while evaluating collaborative design processes, not only the final outcomes but also the gained insights and the achieved `empowerment` through the process should be considered.

Another proposed advantage of collaboration during the design research process is the ability to reveal insights and knowledge otherwise hidden (Sanders and Stappers, 2012). Sanders and Stappers (2012) described three levels of knowledge and explained methods to reach these. As shown in Figure 3-3 these were: 1) what people say (is the explicit knowledge and can be gained by listening to what people say), 2) what people do (can be gained by watching what people do), and 3) the tacit and the latent (is implicit and gained during generative sessions where people create and design).

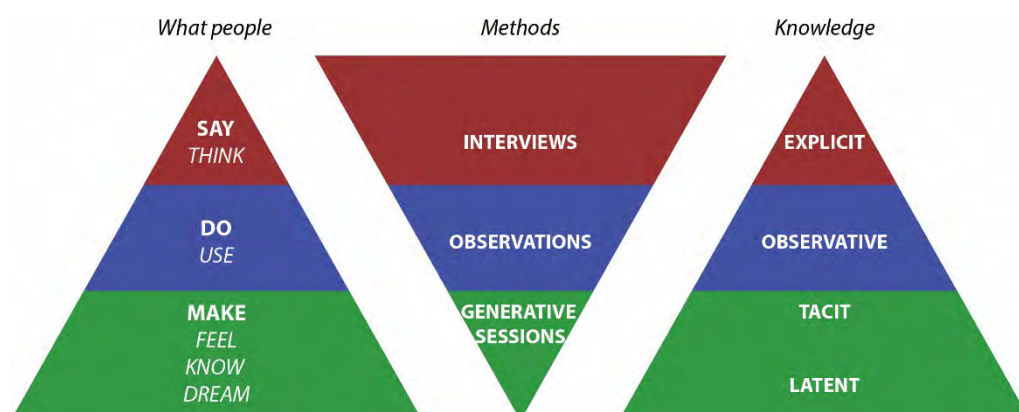


Figure 3-3 Levels of knowledge and methods to access those. Adapted from Sanders and Stappers (2012)

Combining interviews and observations with generative design methods have been proposed as a way to gain tacit insights by facilitating activities for people to make, design

and create. Sanders and Stappers (2008) define co-creation as an “*act of collective creativity*” including all sorts of shared creative activities. They distinguish four levels of collaboration varying according to the interest and expertise of the participants: “*doing, adapting, making and creating*”.

Elements of this PhD was conducted in collaboration with PLWL and their healthcare providers. Their expertise was respected as fundamental and central to this study. Design probes were utilised to facilitate their engagement in the process including scenario-based and cultural probes. A co-making workshop was conducted with PLWL to gain insights about their self-management experience. In reference to Sanders and Stappers (2008)’s levels of creativity the workshop was a collaborative `making` activity.

To summarise, this PhD study followed a reflective design practice led research approach in an iterative manner and in collaboration with PLWL and their healthcare providers. Table 3-2 summarises the mentioned design research approaches and contextualise these in relation to the described three characteristics.

In this section, the characteristics of the followed research approach and the reasons for selecting this particular research route was explained. The next section describes the specific research methods utilised in the study.

Table 3-2 Summary of the Design Research Approaches

Design Research Approach	TRADITIONAL <i>Research about and into design</i>	EVALUATIVE <i>Research for the purposes of design</i>	EXPERIENTIAL <i>Research through design</i>	GENERATIVE <i>Research through design at the front-end</i>
Research Looking Into	How is it (a method, theory, design outcome, process etc.) ...?	How a certain product is (is it usable, easy to use, desirable etc.)?	How a certain product might be better designed?	How a value (health, wellbeing empowerment etc.) might be achieved by design?
3.1.1: Is it future oriented? (Direction of Research)	No (Past and Now): Understanding of the past and the current situation.	No (Now): Understanding of the current situation.	Yes (Past, Now and Future): Understanding of current situation and future possibilities by developing products.	Yes (Past, Now and Future): Understanding of current situation and future possibilities by generating ideas.
Reasoning Approach	DEDUCTIVE What + How = ? (Result)	INDUCTIVE What + ? (How) = Result	ABDUCTIVE 1 ? (What) + How = Value	ABDUCTIVE 2 ? (What) + ? (How) = Value
3.1.2: Is it iterative and reflective? (Source of Knowledge)	No: Research into the design process, design outcomes, methods, history, theory etc.	Yes: Evaluation of prototypes and products can be iterative.	Yes: Reflection while conducting an iterative and collaborative design process to improve products.	Yes: Reflection while conducting an iterative and collaborative design process at the front-end of the process.
3.1.3: Is it collaborative and empowering? (Level of Collaboration)	No: Subject researched into by the researcher.	No: Subject researched for improving a design solution.	Yes: Participants can be a part of the design process and research can be done through their engagement in this process.	Yes: Participants can be a part of the design process and research can be done through their engagement in this process.

3.2 Specific Research Methods

In this section, the research methods followed to collect and analyse data, and the reasons for choosing these methods are explained. Data collection was done through both secondary and primary research methods. The study started by a literature review, which guided the planning of the following primary study. In this study four types of primary research methods were used: 1) observations, 2) interviews, 3) co-making workshop and 4) cultural probe. Table 3-3 summaries these methods in relation to the inquired questions and followed research approaches. Table 3-3 is organised through the structure of the three results chapters of this thesis (Chapters 4, 5 & 6). In addition to these research methods, lymphoedema advocates that were active in online social media platforms have been informally observed, to gain an understanding of the everyday life with lymphoedema. The symptom diaries published by patient advocates have been influential and described in section 6.1.1.

Table 3-3 Research methods, questions and approaches

METHODS	QUESTIONS	RESEARCH APPROACH
CHAPTER 4 - Understanding the Lymphoedema Self-Management Experience		
LITERATURE REVIEW: Systematic selection of the literature describing the experience of PLWL. Thematic analysis of 31 selected articles from the perspective of theories on behaviour, learning, adaptation and socio-psychological (introduced in section 2.3).	- What is the current situation and the available knowledge about the experience of PLWL? - How people experience lymphoedema self-management? (Section 4.1) - What are the facilitators of and barriers to lymphoedema self-management (Section 4.1)	TRADITIONAL Secondary Qualitative Inductive

CHAPTER 5 – Development of the `Model for Empowered Self-management`		
OBSERVATIONS & INFORMAL INTERVIEWS: Observations in 2 lymphoedema clinics and 3 patient events.	- How are the clinical treatments, follow-up appointments and patient-therapist interactions? (Section 5.1)	EVALUATIVE Primary Qualitative Inductive
INTERVIEWS: Semi-structured interviews using scenario-based probes with 9 PLWL.	- Through developing scenario based probes (Section 5.2): How might we design to support the self-management journey of PLWL? - Through interviews with PLWL with scenario-based probes (Section 5.3): How PLWL experience self-management? What successful self-management and empowerment mean for them? How might we design to support the empowerment of PLWL in their self-management?	GENERATIVE Primary Qualitative Inductive and Abductive 2
CHAPTER 6 - Development of the `Design for Empowerment Guidelines`		
WORKSHOP WITH PLWL: 8 PLWL. Picture activity and making wrap-to-measure.	- Through the co-making workshop while PLWL `make` their Wrap-to-Measures: How might we design to support the empowerment of PLWL in their self-management? (Sections 6.1 and 6.2) <i>- Practical Objective: Co-making of a Wrap-to-Measure tailored for each participant.</i>	GENERATIVE Primary Qualitative Abductive 2
CULTURAL PROBE: 6 PLWL self-documented their self-management with the use of `My Lymphy Diary` and the co-created `Wrap-to-measure` for 2 months.	Through the development of the cultural probe (Section 6.1) and through the cultural probe study conducted with PLWL (Section 6.2): How might we design to support the empowerment of PLWL in their self-management?	EXPERIMENTAL Primary Qualitative Abductive 1
INTERVIEWS WITH LYMPHOEDEMA THERAPISTS: 2 lymphoedema therapists	Through the development of the `persona journeys` (Section 6.3) and through the interviews conducted with lymphoedema therapists with the persona journeys (Section 6.4): How might we design to support the empowerment of PLWL in their self-management?	EXPERIMENTAL Primary Qualitative Abductive 1

In the next sections, the research methods followed in this study are described.

3.2.1 Literature Review Method

A literature review of the articles describing the experience of PLWL was conducted. Not having prior experience in working with PLWL, an in-depth understanding of lymphoedema experience was identified as being necessary in preparation to primary studies with PLWL. The literature review asked the following questions: 1) What was the current situation and the available knowledge about the experience of PLWL?, 2) How did people experience lymphoedema self-management?, 3) What were the facilitators of and barriers to lymphoedema self-management?

Literature Screening Process: Articles were screened and selected systematically following the PRISMA protocol (Liberati et al., 2009). The literature search included articles from across seven databases (Pubmed, PubMed Central, Cochrane Library, CINAHL the Cumulative Index to Nursing and Allied Health Literature, Embase and MEDLINE). The following keywords were retrieved with English filter on and for the published articles between January 2007 - November 2017. The following keywords were inquired:

((Lymphedema[Title] OR Lymphodema[Title] OR Lymphoedema[Title]))

AND

(qualitative[Title/Abstract] OR interview[Title/Abstract] OR attitude[Title/Abstract] OR self management[Title/Abstract] OR manage[Title/Abstract] OR self care[Title/Abstract] OR perceive[Title/Abstract] OR perception[Title/Abstract] OR opinion[Title/Abstract])

875 articles were identified from the search. The distribution of the retrieved articles among databases were: Pubmed 197, PubMed Central 13, Cochrane Library 52,

CINAHL the Cumulative Index to Nursing and Allied Health Literature 101, Embase 338, MEDLINE 174.

Initially only abstracts of the retrieved articles were reviewed then the full text of the included articles were assessed for eligibility as shown in Figure 3-4.

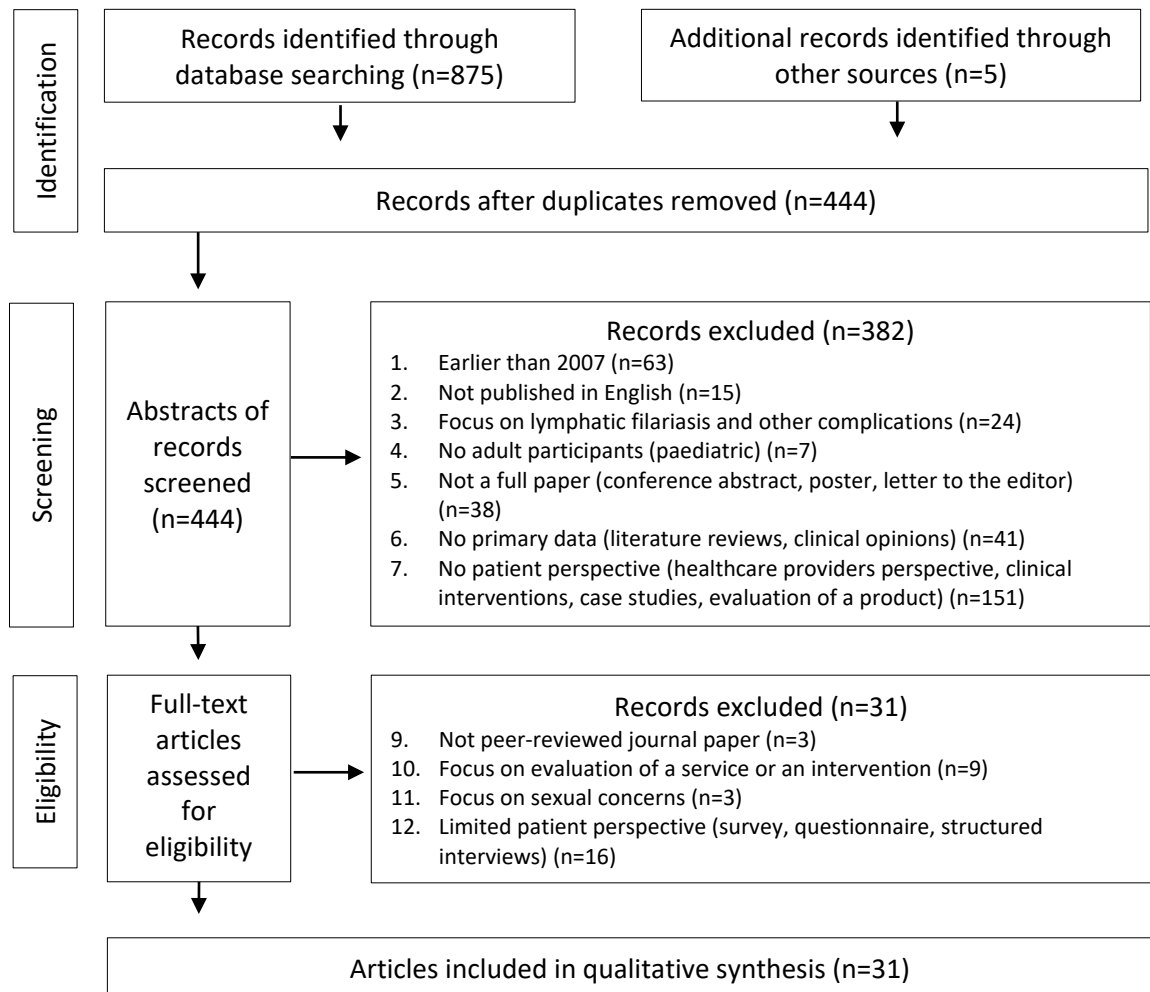


Figure 3-4 Systematic Screening Process of the Literature: Experience of PLWL

Thirty-one articles (listed in Appendix A) were selected as qualifying according to the criteria. To evaluate the quality of these qualitative studies, the following questions as suggested by Mays and Pope (2000) were considered:

- Is the knowledge relevant for this synthesis?
- Are the research questions clear and the research design appropriate for these questions?
- Is the described context of the study adequately?

- d) Is the sampling appropriate for the study?
- e) Is the data collection and analysis described systematically allowing someone else to repeat the study?
- f) Have the authors consciously discussed the impact of methods, their prior assumptions and personal characteristics on the results? (Mays and Pope, 2000)

After the quality assessment, all the thirty-one articles were deemed to meet the criteria and were included in the synthesis.

The studies involved 495 people with lymphoedema, with sample sizes ranging from 3 to 59. Among the 31 journal articles, 26 unique qualitative studies were found. Five studies were found to be published as two separate articles, and both of the articles were included to the thematic synthesis in order to gain a more complete description of these studies. Figure 3-5 shows the distribution of those 26 studies in terms of the type of the lymphoedema of their study participants. In the literature, the studies were found to be dominantly related to Breast Cancer Related Lymphoedema (BCRL), while the number of studies exploring the experience of people with primary lymphoedema was found to be limited.

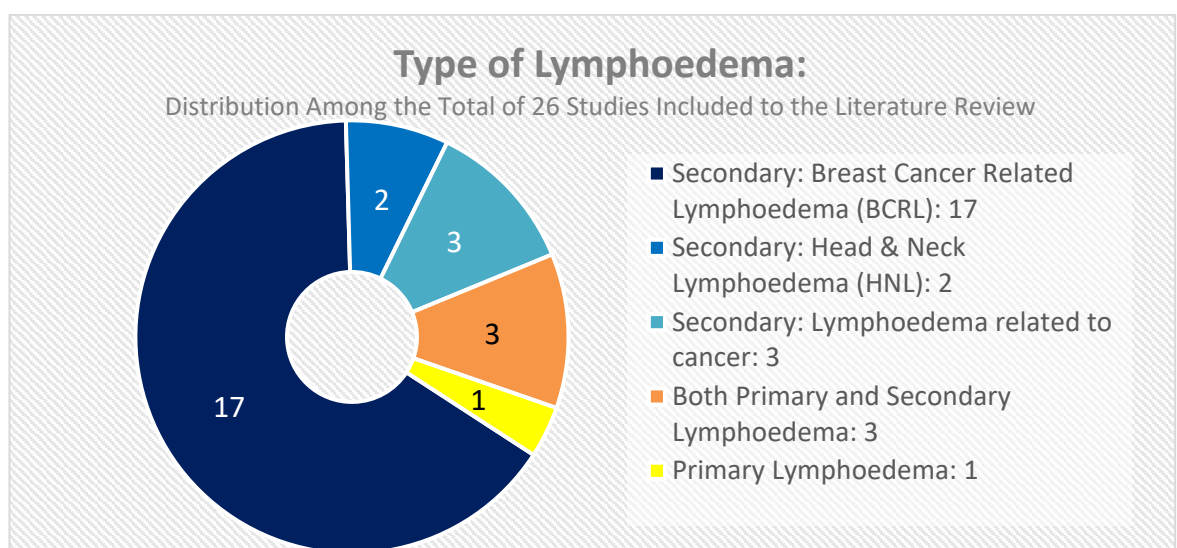


Figure 3-5 Type of lymphoedema of the participants of the reviewed studies

Among the 26 studies, the participants of 12 studies were from USA, 4 studies were from UK, 2 from Canada, 2 from Sweden, 2 from Australia, 1 from Japan, 1 from South Africa and USA, 1 from Netherlands and 1 from Turkey.

Thematic Synthesis Process: Publications were coded following a three staged thematic synthesis as described by Thomas and Harden (2008). The sections of results and findings of the included articles were line-by-line coded. The codes were composed of both direct quotes of patients and results/findings written by the authors. The software Nvivo was used for the coding process. When coding a new article, the existing codes were reviewed to check similar codes created previously. When similar codes were found, their names were reconsidered with the addition of the new code, for better representation of the group of codes. If there were no matching codes, new ones were created. Thomas and Harden (2008) asserted that the primary task in the synthesis of qualitative research was translating the concepts between studies. Codes were organised and renamed iteratively to find better ways to represent codes among multiple articles. These were categorised to form descriptive themes. The final stage of the thematic synthesis was described by Thomas and Harden (2008) as going “*beyond the content of original studies*” by interpreting via specific research questions and the application of theoretical frameworks. During the organisation of the codes, the introduced nine theories related to self-management were influential. These theories were explained in Section 2.3. Finally, all the codes were organised and synthesised to identify: 1) self-management experience and its components, and 2) barriers to and facilitators of self-management. Figure 3-6 presents a screenshot from the start of the third stage of the thematic synthesis process, where the original codes derived from the articles were being organised and categorised. The results of the literature review are described in Chapter 4.

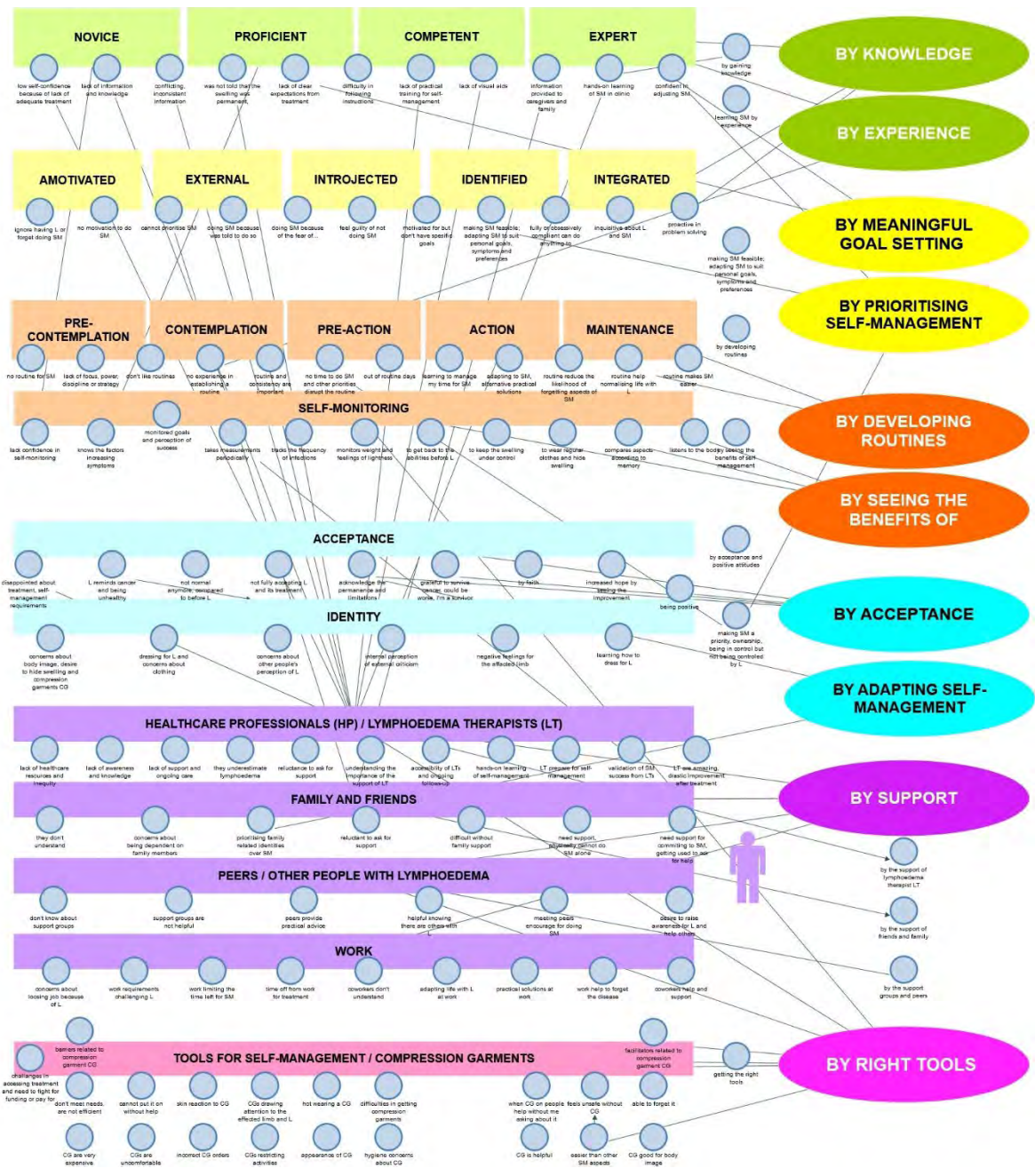


Figure 3-6 Coding for the thematic synthesis of the literature review: An example screenshot from the third stage of the synthesis process

3.2.2 Observations and Informal Interviews

Observations were conducted in this study to build a first-hand understanding of the clinical treatments, follow-up appointments and patient-therapist interactions. Observations

were conducted in two different lymphoedema clinics and three patient-clinician events between September 2017 - March 2018 for a total of six days. Informal interviews were done with lymphoedema therapists to understand their experiences and opinions about self-management. Field notes were taken during and after the observations and informal conversations. These observations and informal interviews influenced the planning of the following primary studies. These studies allowed to gain a first-hand understanding on the ways therapists adapted their support depending on the expertise of their patients, and the discrepancies about the `adherence` to self-management regimes. Reflections on the observations and informal interviews are presented in Section 5.1.

3.2.3 Interviews

3.2.3.1 Interviews with PLWL

Semi-structured interviews with PLWL in individual face-to-face settings were conducted. This approach was selected to encourage participants to articulate their individual self-management experience without influence from others. The literature review and the observations indicated that self-management was perceived private, and individuals could be influenced from the presence of their families or others. Hence, one-to-one interviews were chosen instead of a group approach. Interviews were conducted face-to-face.

Pilot Study: A semi-structured interview script was developed and tested in a pilot interview with someone living with lymphoedema. Questions focused on exploring the self-management experience of the participant in the past and at present, their support needs and suggestions for future systems. The pilot interview was transcribed and thematically analysed. The pilot interview was perceived effective in capturing the

participant's self-management journey, but limited in facilitating conversations about the future of lymphoedema support. The interview script was refined and scenario-based probes were added.

Scenario-Based Probes: Scenario-based probes were chosen to encourage participants to focus and elaborate on `what might support them`. Scenarios are described as narratives describing the artefacts to be used. Scenarios can be generated before the situation they narrate was created, and so they allow to gain insights about future possibilities prior to investment and prototyping (Carroll and Rosson, 1992). With reference to Carroll (2000)'s approach, interviews with scenario-based probes were chosen for this study for the following two main reasons:

- Scenarios have the potential to help envisioning a future use with users early in the product development. Scenarios can be specific to the design of assistive systems and can include features that can only be possible via technologies new to the participants. That can enable gaining insights beyond participants' previous experiences.
- Scenarios have the potential to enable focusing on the intended future user experience, by being flexible about the related products and technologies. This flexibility can facilitate the engagement of users in the manipulation of the scenarios, which allows gaining insights not only about their preferences, but also underlying goals and needs. As described by Cooper (2004) "*tasks change as technology change, but goals have the pleasant property of remaining very stable*".

The scenario-based probes in this study included a persona and cards expressing the features in the scenario separately for a sorting activity. Their development is explained in section 5.2.

Persona: During the interviews with PLWL, the scenario was described as experienced by the persona. Personas are design tools introduced by Cooper (2004) describing behaviours and goals of a hypothetical user. Grudin and Pruitt (2002) explained personas as critical

parts of scenarios, which is founded by research on prospective users. Personas are usually used within product development teams to empathise with the users, communicate user research and discuss design decisions. In this study, unconventionally a persona was presented to the intended users themselves, PLWL. The persona was developed via the voices of PLWL gained from the literature review. Each described attribute in the persona intended to invite participants to talk about specific themes founded in the literature review. The persona in this study aimed to:

- Sensitise participants about their past when they were first diagnosed
- Introduce the literature review results
- Invite participants to discuss their suggestions about how to help someone recently diagnosed
- Facilitate the engagement of participants in the scenario as co-designers by having a segregated actor

Card Sorting: The cards depicted each of the support feature described in the scenario.

Card sorting was selected to complement the scenario by enabling the participant to discuss the features side-by-side. Categorising the cards according to their priority intended to allow the participants to compare them with each other. Participants were encouraged to rearrange the cards after the completion of the scenario, in which they could see all of them together and could talk about the reasons for their categorisation. Blank cards were presented at the end of the scenario for participants to fill and add their ideas to the scenario.

Those scenario-based probes were developed through the voices of PLWL represented in the literature review. The development of these probes is explained in section 5.2.

Interview Structure: Interviews started with open questions about participants'

lymphoedema journey and the following questions were inquired in a semi-structured conversation format:

- How do you find taking care of your lymphoedema at home? Could you compare past (when you were diagnosed) and present?
- How did you learn about managing lymphoedema?
- How do you feel/understand/monitor that your swelling has increased or decreased?
- What are your self-management goals?
- How would you define successful self-management?
- Do people around you ask about your lymphoedema? How do you answer?
- What are the three things that helped you the most in your lymphoedema journey? Why?
- Is there anything that makes managing your lymphoedema difficult? Could you name three things that challenged you the most? How do you think these might be improved, any suggestions for future?
- Is there anything you wish you knew earlier, about lymphoedema self-management? Do you have any advice to people newly diagnosed with lymphoedema?

Following these questions, a visual probe was introduced showing the main themes that emerged from the literature review. Participants' opinion about these themes and their suggestions to facilitate each were solicited. Next, the persona was introduced and participants were asked about their opinions to support the persona in their lymphoedema journey. Finally, the scenario and cards for the sorting activity were presented. Participants were asked about their opinions on each feature described in the cards and sort these into three groups (most important, moderate, not so important). They were prompted to talk about the reasons of their categorisation. Throughout the conversation, they were encouraged to talk about the persona in comparison to their own experience and preferences.

Analysis of the Interviews: All the interviews were audio recorded and fully transcribed.

Data collection and analysis were done concurrently, allowing to add the suggestions of the participants to the scenario and card sorting activity for the following interview.

Transcriptions were coded, following three stages. Initially journey maps were generated for each participant to visualise the key milestones and factors in their lymphoedema journey. Then descriptive themes were categorised. Finally, the codes were interpreted to identify the support needs of participants for self-management. Opinions about these themes were solicited during the workshop study (explained in the next section) and participants confirmed these themes as representative of their experience and as interpreted correctly. The results of the interview study with scenario-based probes are presented in Section 5.3.

3.2.3.2 Interviews with Lymphoedema Professionals

A group interview was conducted with two lymphoedema professionals. `Persona journeys` were used during this study. The design of the persona journeys is explained in section 6.3. Participants received a presentation in advance to the study, which summarised the results of the studies conducted with PLWL, allowing time for reflection. On the day of the study, after open questions about how to support lymphoedema self-management, the persona journeys were presented to the participants. Their opinions about the stages of these personas and ways to support them in their self-management were invited.

The interview took around an hour and was audio recorded. The study was fully transcribed. Transcriptions were coded, following a three-staged approach similar to the interviews with PLWL. The results of the group interview with lymphoedema professionals is presented in Section 6.4.

3.2.4 Workshop with PLWL

A workshop was conducted with PLWL to gain further insights about their self-monitoring experience and to explore ways to support their self-management experience

and empowerment. The workshop also had practical objectives for the study: 1) to create a `Wrap-to-Measure` (a low-tech tool to measure the circumference of the affected limb) tailored for each participant, and 2) to distribute the cultural probe (Wrap-to-Measure and My-Lymphy-Diary) to the participants, 3) to hear participant comments about these probes and answer their questions. The development of the Cultural Probe (Wrap-to-Measure and My-Lymphy-Diary) is explained in section 6.1. The workshop was planned as a `making` level co-creation, which is described as participants' making activity by following a recipe (Sanders and Stappers, 2008). A co-making workshop with PLWL was selected to complement the interviews and observations to gain deeper `tacit` insights during that `making` activity.

The workshop started with a picture association activity. Random pictures cut-out from various magazines were placed on the table and participants were asked to choose from these pictures to describe what lymphoedema meant to them. They were invited to talk about one positive and one negative aspect about lymphoedema.

Then, the results of the interview study were briefly presented by describing the main themes and how that led to the introduced cultural probe. Participants opinions on these themes were inquired. After group discussion, a prototype called Wrap-to-Measure was introduced. Wrap-to-Measure is a tool to self-measure circumference of particular segments of arms or legs. Various materials including fabric in various characteristics, hook-and-loop fasteners, paper tape measures, stickers to mark segments and scissors were provided to the participants. Instructions for making a Wrap-to-Measure were presented and prior made examples were provided. The researcher and two additional facilitators helped the participants while they were making their Wrap-to-Measures.

The workshop took around 3 hours. It was audio and video recorded. Transcriptions were coded, following three stages similar to the analysis described for the interview study. The results of the workshop study is presented in Section 6.2.

3.2.5 Cultural Probe Study

A cultural probe study was conducted with PLWL, to explore design approaches to support their empowerment in self-management. The cultural probe method was chosen as it allows understanding of the participants' engagement with the support approaches in their own personal space and in time.

Cultural probes were originally developed by Gaver et al. (1999). They consist of a variety of materials to aid the participant's self-documentation and to "*provoke inspirational responses*" (Gaver et al., 1999). Unlike other research methods such as interviews or workshops, which take place at a specific time and location, cultural probes are engaged with by participants over time and in their personal space without the presence of a researcher. Previous studies have asserted that self-documentation of people living with chronic conditions is "*closer to real life*" compared to what would have been revealed by participants in an isolated environment (Hassling et al., 2005, Tsvyatkova and Storni, 2014, Mattelmäki, 2006).

Mattelmäki (2006) described four reasons for using cultural probes: to collect information, encourage participation, and stimulate dialogue and for inspiration. Mattelmäki (2006) asserted that participants' observation of their own situation from a different angle and their active participation via self-documentation brought up new suggestions. The cultural probes used in this study intended to:

1. *Collect Information:* Self-management was habitual for the participants of this study, which could be difficult to articulate in an isolated environment. The strength of the cultural probe method in this context was being present in the environment while participants were managing their lymphoedema and without disrupting them. Hence, complementing the interview study, the cultural probe aimed to further explore the everyday self-management experience.
2. *Prompt for Participation:* The cultural probe aimed to invite participants to observe and reflect on their lymphoedema from a variety of different perspectives.
3. *Emerge Dialogue:* The cultural probe study was a part of a continuing collaboration with the participants. The cultural probe was introduced during a workshop in which participants' questions and opinions were solicited and there was an open conversation about the results of the interview study. Participants' anonymised direct quotes from the interviews were included in the cultural probes; hence, their contribution to the development of the cultural probe was made evident to them.
4. *Source of Inspiration:* Participants were invited to annotate and change the cultural probe and suggest improvements over time. Blank pages, and stickers with emoticons and icons were included to gather feedback from participants with different levels of engagement with the probes. Participants were invited to describe their 'magic compression garment' and what they wished they had in the probe. The pages were loose to allow participants to organise the diary in the way they preferred.

My-Lymphy-Diary developed for this study had some similarities with symptom diaries used in chronic condition management. Previously in the literature, the benefits of keeping a symptom diary in chronic conditions were discussed. Lee et al. (2013b) tested a symptom diary intervention with people with heart failure. They reported that the participants with the diary were more likely to take an active role in their self-management

and had fewer emergency events (Lee et al., 2013b). Similarly, Wright et al. (2003) presented that their participants using their symptom diaries knew more about their condition and were more likely to seek help by calling their healthcare provider. Ong and Jinks (2006) analysed the open diaries of people with knee pain. They discussed the benefits of open diaries as enabling patients to describe their own priorities and healthcare providers to comprehend their lived experience with a broader scope (Ong and Jinks, 2006). Frank (2004) emphasised that people needed to express their healthcare related stories to re-invent their identities after diagnosis. The cultural probe included sections for such expressive writing as well as several ways to monitor symptoms. The development of My-Lympho-Diary and Wrap-to-Measure is described in section 6.1. Their development was informed by theoretical models and existing symptom diaries used by PLWL.

The cultural probe was introduced to the participants during the workshop. It consisted of My-Lympho-Diary and Wrap-to-Measure. The provided cultural probe package included a pre-paid return envelope and participants were requested to send their cultural probes within two months. An e-mail to remind participants about the cultural probe was sent after the end of the first month. The results of the cultural probe study is presented in Section 6.2.

3.3 Ethical Considerations

Ethical approval was sought for the study following Cardiff Metropolitan University's procedures. In the ethical approval document the research design and considerations for dealing with potential risks were described. An information sheet and consent form were provided to the participants prior to the study (Appendix B). The information sheet explained the study, what was expected from the participants and how their privacy would be protected. Participants were aware of the opportunity to withdraw at

any stage of the study without giving a reason. All participants provided informed written consent prior to participation.

3.4 Participants

In this section, the approach in selecting study participants and their recruitment process is explained.

Involving patients in design research has been perceived as challenging. Groeneveld et al. (2019) described one of the barriers as patients not being used to engaging in design activities and creating solutions for themselves. Yet, some people were discussed to be better able to collaborate in creating such solutions compared to others (Von Hippel, 1986, Pascale et al., 2010). According to Pascale et al. (2010) people who were facing the needs earlier than their peers and “*succeed against all odds*” were “*positive deviances*” and collaboration with these types of individuals were seen as more effective in design research activities. The positive deviance approach was utilised within healthcare services to uncover how they succeeded despite having the same resources, and to disseminate these strategies to other groups (Craig and Chamberlain, 2020, Baxter et al., 2015). Graffigna and Barelo (2018) explained that patients who were advocating and proactively seeking solutions for their healthcare were better able to collaborate in producing new solutions. Hence, during the recruitment phase of this PhD study, people who were attending conferences and peer support groups were preferred. Individuals at a conference and a support group were hypothesised to be more likely to be proactive in self-managing their lymphoedema and solving their problems.

Convenience sampling was followed. No exclusion criteria were set. PLWL of both primary and secondary causes, and having lymphoedema in their arm(s) or leg(s) were included. As shown in Figure 3.5, the lymphoedema literature was predominantly

concerned with secondary lymphoedema, and mostly on Breast Cancer Related Lymphoedema (BCRL). However, studies exploring the experience of people living with primary lymphoedema were limited. Hence, an even representation of primary and secondary lymphoedema was an intention of the study.

The study was explained to a local lymphoedema support group and the information sheet was handed to them. Similarly, at a lymphoedema conference, the study was explained to potential participants with lymphoedema who were interested in the study. A total of 10 PLWL participated in the studies (interview, workshop and cultural probe) as listed in Table 3-4. All the study participants were female.

Table 3-4 List of study participants with lymphoedema

Pseudonyms*	Interview	Workshop	Cultural Probe	Age (years)	Affected Limb	Lymphoedema Type	Years Since Diagnosis
Sarah	Pilot	✓	✓	70-80	Leg	Primary	>40
Margaret	✓	✓	✓	70-80	Arm	Secondary	<5
Mary	✓	✓	✓	60-70	Leg	Secondary	>5
Elizabeth	✓	✓	✓	60-70	Leg	Primary	>15
Jennifer	✓	✓	✓	60-70	Leg	Secondary	>30
Laura	✓	–	–	30-40	Leg	Primary	>5
Helen	✓	–	–	40-50	Leg	Primary	>20
Lesley	✓	✓	–	70-80	Leg	Primary	>10
Carol	✓	✓	–	60-70	Leg	Secondary	>10
Angela	–	✓	✓	not known	Leg	Secondary	not known

**Pseudonyms were assigned to participants to keep their identity anonymous.*

Two lymphoedema professionals participated to the group interview. Sharon and Susan (pseudonyms) had around 15 to 20 years of experience in providing care and therapy for PLWL, and they were working together as a part of a team.

3.5 Methodological Limitations

Convenience sampling was followed for the selection of study participants, which posed some limitations. The PLWL who participated in this study were part of a support group or were taking part at a patient education event. Hence, people who did not have access to such support or did not prefer to join were not represented. Studies were conducted with PLWL living in the United Kingdom (n: 8) receiving care in the National Health Service (NHS) and in the European Union (n: 2). All the study participants were women. Only one of the participants had lymphoedema on her arm; the other participants had symptoms in their leg(s). These may limit representation of different types of lymphoedema, countries with different health care systems and people of other cultures or language groups. The sample size was 10 individuals with lymphoedema and 2 lymphoedema professionals. To overcome some of the limitations of the participant sampling, a literature review of the systematically selected articles was conducted, which allowed to check relevance to the lymphoedema experience of wider demographics.

Another limitation was related to the study being carried out at the front-end of the design process and its generative nature. The probes used in the studies were intentionally not developed design solutions. Thus, participant comments were about their intention-to-use and perceived usefulness (their thoughts about using these), which may have been different to their real use behaviours (how it is when really used them). Hence, these comments were not considered as particular to evaluating the ideas represented in the probes, instead these have been apprehended as insights about the self-management experience and approaches to support that experience.

3.6 Chapter Summary

In this chapter, the characteristics of the design research approach followed in this study was contextualised and explained. This PhD undertook a research through design approach at the front-end of the design process. It was conducted with the involvement of PLWL and their healthcare providers. Both secondary and primary research methods were conducted to inquiry the research question and in an iterative manner. These research methods and the reasons for selecting them were described. Selection of the participants for these studies were described in this Chapter. The results of these research studies are presented in the following three chapters (Chapters 4, 5 and 6). Figure 3-7 shows the followed research path, and the related Chapters that present the results of these studies.

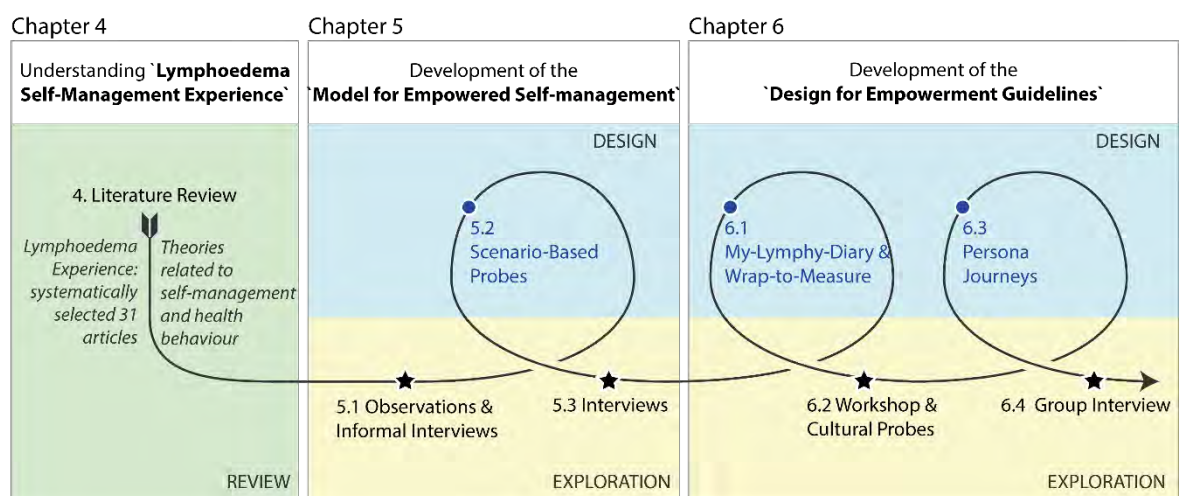
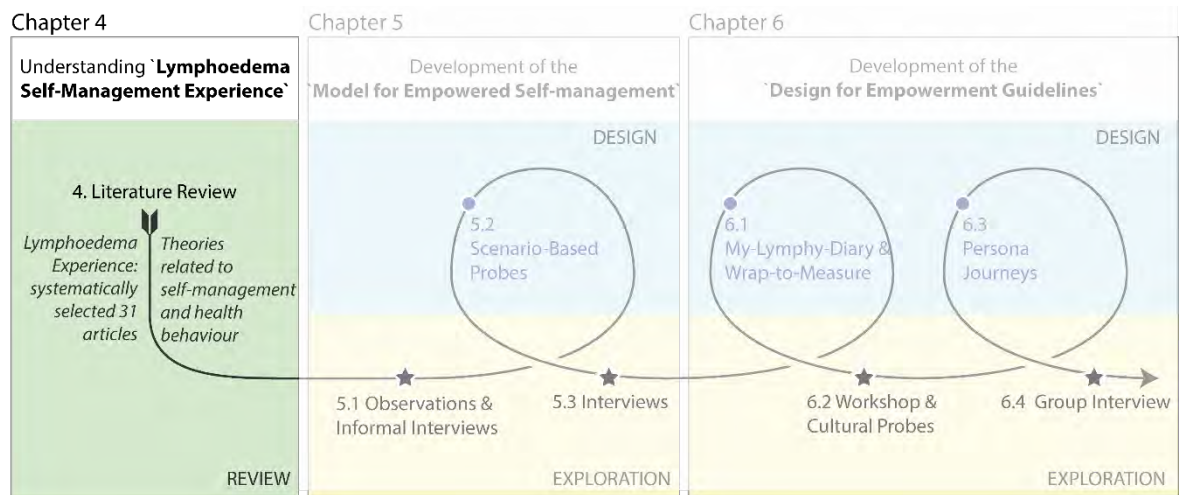


Figure 3-7 Research Path of the PhD and the Structure of the Result Chapters

Chapter 4 Understanding the Lymphoedema Self-Management Experience



This chapter presents the results of the literature review conducted to understand the lymphoedema self-management experience. In preparation for the primary studies with PLWL, a wide range of qualitative studies were systematically reviewed. Arising from this review 31 qualitative articles were selected that presented in-depth descriptions of the lived experience of adults with lymphoedema (selected articles listed in Appendix A). The systematic selection method of these articles are described in section 3.2.1. These articles were thematically synthesised following three stages as discussed by Thomas and Harden (2008). During the final phase of the thematic synthesis, the themes were interpreted to address the following two study objectives: 1) To identify the facilitators of, and barriers to, lymphoedema self-management, 2) To understand and map the lymphoedema self-management experience. The second objective was achieved by analysing the literature that described experiences of PLWL, from the perspectives of theories related to the self-

management experience. These theories included behavioural, adaptation and social-psychological theories, and were introduced in section 2.3.

Table 4-1 Components, Barriers and Facilitators of Lymphoedema Self-management

	COMPONENTS	BARRIERS	FACILITATORS
4.1	COMPETENCE: Novice to expert	Instruction-based delivery of information	Hands-on demonstrations and visual materials
		Conflicting or insufficient information	Being proactive in problem-solving and finding alternative sources of information
4.2	AUTONOMY: Extrinsic to Integrated Motivation	Lack of clear expectations from self-management	Having an understanding of the consequences of not doing self-management
		Not being able to observe change despite practicing self-management	Seeing the benefits of self-management
4.3	HABIT: Intention to Action	Lack of time, discipline and routine	Building Habits
4.4	PSYCHOLOGY: Overwhelmed to Coming to Terms with	Overwhelmed about having the condition	Coming to terms with having the condition
4.5	IDENTITY: From Disruption to Re-invention	Self-management contradicting with preferred 'normal' identity	Adaptation of self-management strategies to confirm 'normal' identity
4.6	SUPPORT NETWORK: Towards Collaborative Care	Limited support and underestimation of the condition	Well-informed and collaborative support

The literature review evidenced that PLWL were going through a journey while adjusting to life with lymphoedema and gaining expertise in self-managing this chronic swelling. The synthesis generated six components as fundamental in this experience:

competence, autonomy, habit, psychology, identity and support network. These components were selected based on being common among lymphoedema self-management experience as described in the synthesised articles and in correspondence with the theories. In Appendix C, related key quotes were shown, presenting the voices of PLWL that were central in distinguishing these themes from the articles. The narratives of PLWL in the synthesised articles were analysed to identify the barriers and facilitators of lymphoedema self-management. Eight themes emerged as pairs of opposing barriers and facilitators. Together with the theoretical perspectives, these barriers and facilitators were distinguished within the six components of the self-management experience (Table 4.1).

4.1 Competence: Novice to Expert

Competence, as a component of the lymphoedema self-management experience meant developing self-management skills, and the extent of feeling physically and intellectually capable of managing.

According to the narratives of PLWL in the synthesised articles, two main types of skills were required to self-manage lymphoedema. The first type of skills were about learning how to perform the recommended management strategies, such as how to wear compression garments and do the Simple Lymphatic Drainage (SLD) massage. The second type of skills were situational. These were about problem-solving and decision-making when the symptoms change and during out-of-routine occasions.

Dreyfus and Dreyfus (1980)'s `Skill Acquisition Theory` (Section 2.3.1), Kolb et al. (2001)'s `Experiential Learning Theory` (Section 2.3.2) and Graffigna and Barelló (2018)'s `Patient Health Engagement` model (Section 2.3.9) were highly influential in the categorisation of the competence component of self-management that emerged from the analysis. Three stages were distinguished within the process of developing competence for

lymphoedema self-management: novice, proficient and expert. Key quotes of PLWL from the synthesised articles that lead to these stages are listed in Appendix C1.

4.1.1 Novice

The narratives of PLWL in the synthesised articles showed that for many people, even receiving a diagnosis and consistent information about how to manage their conditions was a struggle. PLWL described the occasions when they received conflicting or insufficient information from their healthcare professionals, which delayed their lymphoedema diagnosis and hindered the management of the condition:

You get an answer from a specialist, "Ah no, I don't know how to treat that," or, "We don't do that any more." And the other [specialist], "No, I don't think the decongestive therapy will help you." And [the lymphedema therapist] told me, "Yes, I think it can help you." So you say, you know, where's the error? (Towers et al., 2008)

Yet, even after a clear diagnosis and information on managing lymphoedema were provided, this was frequently not perceived adequate or sufficient for self-managing the condition. According to Dreyfus and Dreyfus (1980) novices knew rules but could not correlate these with specific situations. This corresponded to the accounts of PLWL who described that some strategies were explained to them, but they did not know yet how to implement these or did not experience their outcomes yet. Dreyfus and Dreyfus (1980) emphasised that context of the rules should be provided with real world examples to facilitate learning. PLWL mentioned the importance of visual aids and practical training in which they were able to see, try and feel. Hands-on demonstrations were also important for PLWL, to get used to the changes lymphoedema brought to their body: *"I didn't know how much I was allowed to touch, push, can scars open up, can it become inflamed. I didn't know my new body in that way"* (Karlsson et al., 2015). PLWL expressed that they found it

difficult to follow instructions. They explained that, even though they thought they were given clear instructions when at the clinic, they could find these difficult to follow when they went back home to manage the condition themselves:

I thought that my therapist gave me very clear instructions to follow when I finished my first round of therapy. But once I was on my own I found the reality so different. For example, for months and months it took me so long to get my sleeve on that I became frustrated. (Fu et al., 2010)

4.1.2 Proficient

At the proficiency stage, PLWL had some knowledge, skills and experience in practicing cornerstones of self-management; but they were not competent in managing fluctuations yet. PLWL explained how they learned by hands-on training provided by their lymphoedema therapists, conducted their own search and developed their own techniques by experience. Experiential learning was described as central for PLWL for exploring the strategies that were effective for themselves.

Lymphoedema treatment is described as a process in which one needs to figure out which parts of the treatment give one the desired effect. There is also an understanding of this process and a realisation that everyone's lymphoedema is different. (Karlsson et al., 2015)

Experiential learning was a cycle of `active experimentation` and `reflective observations` according to Kolb and Kolb (2005). In lymphoedema self-management, that was done by trying out management strategies and observing the results of these. PLWL observed and monitored their swelling primarily by “size, appearance, internal sensations, and the feel or consistency of their swollen limb” (Jeffs et al., 2016). Clinical assessments included taking measurements of the affected limb and comparing that with the unaffected limb and previous numbers. These clinical measurements were perceived to be critical by some PLWL: “I may not notice it, but a tape measure would” (Jeffs et al., 2016). Yet,

according to one participant in Jeffs et al. (2016)'s study the sensations could also be perceived differently, when compared to the clinical measurements.

When I've come and told the nurse here I think my arm is quite swollen she measures it up ... and will say, 'Oh, it's only about 30 or 50 mls difference in volume.' ...if you measure it in a glass of water, [that] is pretty small ... but the impact I think is way more than what the volume states. (Jeffs et al., 2016)

When PLWL had trouble in finding reliable information about their condition from healthcare professionals, some sought alternative sources. PLWL explained how they found out about managing their lymphoedema from sources including internet, self-help groups, books and conferences:

I called my therapist and she just said: 'It should be better once you get used to it.' One day, I was surfing online and found X, which changed my life. I found it just takes a few minutes for me to put on my sleeve. I wish I had been told about this along with all the other instructions at the beginning. (Fu et al., 2010)

In the proficient stage, PLWL were competent in practicing self-management as prescribed. Yet, unanticipated symptoms and occasions could be difficult to manage. Graffigna and Barello (2018) described in their Patient Health Engagement model that individuals who were formally adherent to their self-management without totally grasping the reasons of performing these self-management strategies, might not be able to adapt their strategies to manage unexpected events. Comprehending the influence of the particular management strategy and triggers on the symptoms, contributed to the development of expertise in self-management.

4.1.3 Expert

The expert stage in lymphoedema self-management was expressed as feeling competent in making self-management decisions despite fluctuations, having strategies for a variety of different occasions and the ability to adapt these for changing situation. One

participant in Jeffs et al. (2016)'s study explained that through observation of the onset of her swelling, she was able to take precautions:

First, an awareness of internal sensations (fullness, then ache or heaviness in the arm), changes to the tissues and, if remedial action not taken, increased hand size and loss of definition of knuckles and veins evident by the end of the day. She had noticed that increased hand swelling was more likely to occur on days when she was busy and did not pay attention to the onset of internal symptoms. She believed these internal sensations were an early warning sign and that, by paying attention and taking early action (extra exercise or SLD), she could avoid exacerbation of swelling. (Jeffs et al., 2016)

Some PLWL recognised that there were times in which they could not be diligent enough in their management. Yet, their competence in being able to compensate such occasions was enabling them to adapt their management: *"I'm careless sometimes, but then I know how to get on the right path again..."* (Karlsson et al., 2015). PLWL expressed how they learned to be proactive in planning for holidays, flights or other out-of-routine occasions. For instance, experiencing the difficulties of not having access to medications when needed abroad, they were planning ahead and supplying these prior to their trips.

4.2 Autonomy: Extrinsic to Integrated Motivation

Autonomy as a component of the lymphoedema self-management experience meant the extent of feeling responsible, motivated and in-control of managing one's own condition.

The synthesised articles showed a variety of reasons for practicing lymphoedema self-management including to avoid infections, avoid progression of the swelling, increase independence, wear regular clothes and get back to 'normal'. The support of healthcare professionals and seeing the benefits of self-management were described as the main sources of motivation. Previously in the literature individual's confidence in being able to manage their lymphoedema and their self-efficacy, was shown to increase their self-management behaviour/practice (Sherman et al., 2015).

Ryan and Deci (2000)'s 'Self-Determination continuum' (Section 2.3.4), Bandura (1977)'s 'Self Efficacy' (Section 2.3.5) and Hibbard et al. (2004)'s 'Patient Activation Measure' (Section 2.3.8) were highly influential in the categorisation of the autonomy component of self-management. Three stages were distinguished within the process of developing autonomy for lymphoedema self-management: amotivated, extrinsic and integrated. Key quotes of PLWL from the synthesised articles that lead to these stages are listed in Appendix C2.

4.2.1 Amotivated

According to Ryan and Deci (2000) lack of motivation could be the result of not finding the outcome valuable or not feeling competent to achieve that outcome. Amotivation towards lymphoedema self-management occurred for reasons including difficulties in prioritising among other duties, not having clear expectations, feeling unable to manage and not seeing any benefits: *"Lymphoedema seemed to be something like an incoming tide; ... there didn't seem to be anything you could do about it."* (Meiklejohn et al., 2013). Some PLWL explained that they did not perceive some of the self-management strategies beneficial for them. One of the participants in Jeffs et al. (2016)'s study explained:

I haven't done any SLD [Simple Lymph Drainage]. The massage was really, really, really boring, because the movements are so minute and exact and I couldn't accept ... though you know the professionals that are saying it works, but I can't quite believe it because it feels like you're doing absolutely nothing. (Jeffs et al., 2016)

Some PLWL explained that they could not observe any change despite doing the self-management strategies as instructed: *"I did wrapping for a while. It was not particularly effective for me"* (Fu, 2010). Not seeing the results of the treatment was causing PLWL to feel demotivated.

In their patient activation measure Hibbard et al. (2004) defined a `passive` stage where patients were recipient of care. Hibbard et al. (2004) described the recognition of being the responsible person for managing one's own condition as an important step towards patient activation. That corresponds to the accounts of PLWL, in which they explained their expectations to be taken care of and treated by someone else as a barrier to self-management:

... I imagined getting a treatment like this, treatment, a treatment where I could lie on the bed and get treated and then go home. It was a bit shocking, like oh God do I have to work a lot with myself and do I need to wear this sock, that's what the treatment is (Karlsson et al., 2015)

4.2.2 Extrinsic

The accounts of the participants of the synthesised articles described a stage where individuals could be practicing self-management because they were told it was necessary and felt guilty when they were not following the advice of their healthcare professionals. These were corresponding with Ryan and Deci (2000)'s extrinsic motivation continuum. For PLWL, practicing self-management just because they were told to was expressed not to be effective for long-term continuation.

I did wrapping for a while. It was not particularly effective for me but I did it because I was told to. Wrapping is time-consuming and awkward, so it's not just down to whether I can do it or not — I was actually depleted by wrapping. (Fu, 2010)

After individuals started performing self-management, whether or not they were left feeling as if it was successful was influential in gaining autonomy. Bandura (1977) named that factor “*performance accomplishments*” and described that if people had performed well previously at a task, they were more likely to feel competent and perform that again. PLWL in the synthesised articles expressed that they felt motivated and hopeful when they saw the benefits of self-management. However, lymphoedema self-management

was a long-term investment and not seeing the benefits in a short time was a barrier for some.

The narratives of the PLWL in the synthesised articles presented that many were anxious about the consequences of not managing their condition. Even though that was perceived overwhelming, it was also expressed to be their reason for managing their condition. PLWL explained that experiencing the burden of the symptoms when not managed and their concern about possible complications were motivating them to manage:

I take care of my arm in case I lose it or it is amputated. Each time I remember this, I stick to exercising, applying cream, and taking care of my arm, but I may skip some of them after a while. (Cal and Bahar, 2016)

4.2.3 Integrated

Ryan and Deci (2000) described that integrated motivation occurred when the value of the activity was “*assimilated to the self*”. Some accounts of PLWL expressed such ownership of managing their condition and perceiving it as a part of their life.

You need to be on top of it . . . it's part of your life, but it doesn't need to be all-consuming... Lymphedema is as much of a handicap as you let it be (Bogan et al., 2007)

Seeing the benefits of lymphoedema management was a strong facilitator described by PLWL. They were motivated by seeing the decrease in their swelling and also by experiencing the improvements that had for their quality of life. When clinical treatment was perceived effective, they were also more eager to self-manage to maintain these results in the long term:

It [lymphoedema] nearly finished my career (...) the treatment has already made a difference to my life what they have done in the last few months here and I wish it had happened sooner. (...) I have never seen my leg and ankle so small and I sometimes just stand and look at in the mirror because I can't believe it and it just gives me a bit of hope. (Watts and Davies, 2016)

Integrated motivation for PLWL meant self-management becoming more than a matter of compliance, but how individuals made it feasible and integrate that to their life: *“This is not an issue about whether or not I have listened to my therapist, but how can I best make this work”* (Fu, 2010).

4.3 Habit: Intention to Balanced Habit

Habit as a component of the lymphoedema self-management experience meant the actual performed action and the extent of this becoming a habit.

Prochaska and DiClemente (1983)’s Stage of Change Model` (Section 2.3.3), Graffigna and Barello (2018)’s `Patient Health Engagement` (Section 2.3.9) and Hibbard et al. (2004)’s `Patient Activation Measure` (Section 2.3.8) were influential in the categorisation of the habit component of self-management. Key quotes of PLWL from the synthesised articles in relation to the stages of the habit component is presented in Appendix C3.

4.3.1 Intention

Prochaska and DiClemente (1983) suggested five stages for sustaining a health behaviour change. According to their model, during the first three stages individuals were building intention for change and getting prepared for action. Intention was defined as prerequisite of behaviour by Ajzen (1985)’s theory of planned behaviour. The theory suggested that individuals with an intention to perform a behaviour would then assess the factors facilitating or impeding their behaviour.

The narratives of PLWL in the synthesised articles presented that having an awareness and intention for managing lymphoedema did not always mean taking action.

I lack the self-discipline to place my health first in my life. I was taught from a very early age that work is most important and I guess that lesson stuck. I need a way to rearrange my life. (Radina et al., 2014)

Barriers included lack of time, discipline and routine: *“I’m struggling to find time to do it [simple lymph drainage massage] because I do a full time job and I’ve got two teenage children, is like all hands on all the time.” (Jeffs et al., 2016).*

4.3.2 Adhesion versus Experiential

From the comments of the PLWL, two types of paths in starting to build a self-management routine were distinguished: adhesion and experiential. Both of these paths shared the characteristics of developing routines, but not being able to manage unexpected events yet. Adhesion was when individuals performed self-management totally (and sometimes obsessively) as prescribed/advised to them. Experiential was when they had a gradual, and trial and error-based approach to self-management strategies.

In the definition of the **adhesion** stage the Patient Health Engagement Model of Graffigna and Barelo (2018) was influential. They described people at this stage as *“formally compliant”* with their self-management. According to Graffigna and Barelo (2018) at the adhesion phase the focus would be on the person as a ‘patient’. They explained that at this stage people did not totally grasp the reasons for and outcomes of performing these management strategies, and hence were unable to adapt these without the support of a healthcare provider when unexpected symptoms occurred (Graffigna and Barelo, 2018). The comments of PLWL in the synthesised articles demonstrated that some individuals described such a phase where they compulsively performed self-management, which later they adapted and made them feasible for continuation. That was illustrated as follows by one of the participants of the synthesised articles:

I would say my treatment, what I was doing, was quite intense because I was almost fanatical about it. You tend to think it runs your life (...) it was getting in the way at first, you know, I was quite uptight about it at first. (Jeffs et al., 2016)

Kolb et al. (2001)'s experiential learning theory was influential in the definition of the **experiential** phase. According to Kolb et al. (2001) people learned via observing and reflecting on their experiences and experiments. Corresponding with their model, the synthesised articles described how PLWL observed the influence of management strategies in their swelling by using *"trial and error to determine the minimum effort required to maintain an acceptable level of swelling"* (Jeffs et al., 2016). PLWL explained the strategies that they found out from alternative sources of information, from other PLWL and by themselves:

I just put it right there under my eye, and it just makes it easier to work with the skin and get it to smooth out easier. But I came up with that one on my own because they didn't use; they didn't use anything to do it. They just had the touch, they just knew how to do it. (Deng and Murphy, 2016)

4.3.3 Balanced

Unlike the adhesion stage in which individuals' focus was on being a `patient` who complies with prescribed self-management strategies, at the balanced stage their focus was on being the `person` living `as normally as possible` by managing their condition. In this stage the prior experimentations of the PLWL pays off by allowing them to build an effective and balanced self-management that is integrated into their life, instead of dominating it or being a hindrance:

I just try and live as normal as possible, but obviously it's like restrictions. It's not going to run my life. It's not going to be one of those things you say I can't do that because I've got lymphoedema ... It's [the sleeve's] part of my everyday life now. It's just there and you just do it. (Jeffs et al., 2016)

At the balanced stage, PLWL were continuously observing the influence of the strategies and possible triggers in everyday life, to further improve their self-management,

and to find more effective and feasible ways to control their swelling. Adaptation of self-management to make it feasible, and to integrate it to everyday life was a frequently-mentioned strategy among PLWL. In one of the synthesised articles, Fu (2010) described that approach in contrast to the medical perspective of non-compliance:

For the women, managing lymphoedema was more complicated than simply complying with the treatment or prescribed daily regimen. Instead of passively following healthcare professionals' instructions, the women actively and creatively structured their lives to 'make lymphoedema care feasible'. The women did not consider selectively carrying out the prescribed daily regimen as non-compliance, but rather as a way of using strategies to 'make daily care feasible'. (Fu, 2010)

Another criteria described in the balanced stage was having a consistent routine.

Wood et al. (2002) compared the habitual and intentional behaviours and explained that when actions were performed automatically as a habit, that was potentially allowing people more resources for other everyday activities and decisions. That corresponded to the comments of PLWL in the synthesised articles, expressing that building routines made self-management easier for them:

Before I get dressed or anything else, I do the exercise and it's just part of my morning routine. And I think it's that routine-ness of it, you stop thinking about it, you just do it. And I think that makes life a lot easier. (Jeffs et al., 2016)

They described integrating self-management to everyday habits, also as a way to live a 'normal' life with lymphoedema (Jeffs et al., 2016). Another advantage of a consistent routine was described as being able to better manage by not allowing the fluid to build up over time. One of the participants in the study conducted by Deng and Murphy (2016) explained:

The thing that I find the most effective is to develop a routine and stick to it, you know. In other words, don't do it once a week, you. You're gonna be climbing uphill the whole time, you know. If you get it under control it's easier to keep it there than it is to just let it slip and then try to catch it back up. So yeah, get develop a routine and just and and accept the fact that you are going to be doing it the rest of your life. (Deng and Murphy, 2016)

4.4 Psychology: Overwhelmed to `Coming to Terms with`

Psychology as a component of the lymphoedema self-management experience meant the psychological and emotional state of people in relation to their chronic condition.

Graffigna and Barello (2018)'s Patient Health Engagement Model (Section 2.3.9), and Kübler-Ross and Kessler (2005)'s Five Stages of Grief Theory (Section 2.3.6) were influential in the definition and categorisation of the narratives of PLWL about their psychology of having and managing lymphoedema. Key quotes of PLWL from the synthesised articles in relation to the stages of the psychology component are presented in Appendix C4.

4.4.1 Overwhelmed

PLWL expressed their frustration and anger towards having a permanent condition, the limitations lymphoedema brought to their life and the burden of managing it on a daily basis. They described that they felt sad about not being able to get back to their `normal` quality of life and depressed about how big their affected limbs could become in the future. Initial responses to the diagnosis could be denial, one of the participants of Fu (2010) explained: *"At the very beginning, I thought, 'if I ignore or neglect it [lymphoedema], I should be better.' So, I kept doing what I was not supposed to do"*.

The accounts of PLWL in the synthesised articles showed differences according to the type of the lymphoedema being primary or secondary, and how the onset and diagnosis of the condition was experienced. The synthesised articles were dominantly carried out by participants with secondary lymphoedema. Among the 31 analysed articles, only one article focused exclusively on primary lymphoedema experience. Three articles had participants with both primary and secondary lymphoedema. Hence, the literature was very

limited in expressing the experience of people living with primary lymphoedema. Yet, the responses of participants with primary and secondary lymphoedema presented a very different journey. People with primary lymphoedema in the synthesised articles had been suffering from the condition for at least five years, without knowing why their limbs were swelling or how to manage that. Hence, for some people with primary lymphoedema the diagnosis was perceived as a relief and a source of hope for finally being able to manage their swelling. One of the participants in Bogan et al. (2007)'s study described how she diagnosed herself via internet and how that diagnosis made her feel:

I was so relieved when I found out that I had lymphedema. I mean, it's not something to be happy about, but I was happy. That I wasn't going crazy, that there really was something wrong with my legs (Bogan et al., 2007)

Conversely, if lymphoedema was secondary due to cancer treatment, diagnosis was usually instant. Some PLWL expressed that they were grateful to beat the cancer and were positive about managing their lymphoedema. Yet, for most of the others, the sudden changes brought by lymphoedema and the permanence of the condition was perceived to be overwhelming. This was particularly evident where the individual was not warned about the risk of lymphoedema prior to cancer treatment; they often perceived lymphoedema as a fault of their surgeons "...I had not been warned of the possibility [of lymphoedema], I still feel great anger" (Barlow et al., 2014a). PLWL after cancer treatment frequently described lymphoedema as a constant reminder of cancer and worse than that:

Having cancer is not as bad as having lymphedema. The breast is gone, the treatments are over and it is in the past. Lymphedema on the other hand is constant... I now had a physical reminder of my journey through hell. My constant companion, an enlarged arm, was a continuous reminder. (Ridner et al., 2012)

4.4.2 Reconsidering

PLWL expressed that even if they acknowledged the permanence of their condition, their frustration could be ongoing. They could swing between being hopeful about overcoming lymphoedema to desperation of not being able to have their `normal` life back: *“Sometimes I feel I can beat this, other times I feel like giving up on life. This has been the hardest thing I have ever gone through in my life”* (Maxeiner et al., 2009). The reasons for frustration included the occurrence of symptoms, being unable to do what they wanted to do or feeling unsuccessful in managing:

I was a bit sad when I didn't succeed in getting rid of it, but I thought if I go home and work with stroking my body and the movements that I've been given then maybe it will improve, but it got worse. (Karlsson et al., 2015)

4.4.3 Coming to terms with

`Coming to terms with` was a milestone described in relation to accepting the permanence of the condition and taking control of one's own care. One of the participants in the study conducted by Jeff et al. (2016) explained:

I suppose knowing that you've got to live with it, but it's a forever, ever and ever thing isn't it. (...) I think something clicked in the brain... got to accept it first, then tackle it and then get the results. (Jeffs et al., 2016)

Some PLWL explained their frustration because of the underestimation of the severity of the condition: *“...the thing that changed my life the most was lymphedema and they always give me the impression that I should be grateful that's all I had”* (Greenslade and House, 2006). Some others expressed that they were thankful to be a cancer survivor, even if that included dealing with lymphoedema:

I am living with this condition everyday but not as an invalid but as a survivor. God spared my life and lymphedema was part of the package. That's OK when you consider the alternative. (Ridner et al., 2012)

Some PLWL expressed that they accepted having a chronic condition and were managing their swelling as a part of their everyday life: *“It's part of getting dressed in the morning. It's like somebody who has one leg. They have to put on their prosthesis in the morning. I have to put on my sleeve”* (Hamilton and Thomas, 2016).

4.5 Identity: Disruption to Re-invention

Normalisation as a concept means two kinds of process in patients' experience of chronicity. On the one hand patients may well try to 'normalise' in the sense of keeping their pre-illness lifestyle and identity intact... But normalisation may also mean the incorporation of illness into the patient's changed lifestyle. 'Normal life' is redesignated as containing the illness, and being open about it. (Bury, 2001)

Identity as a component of the lymphoedema self-management experience meant the individuals' adaptation to changes in their social roles and identities after the diagnosis of their chronic condition.

The responses of PLWL from the synthesised articles described how their lymphoedema experience was socially constructed. Lymphoedema self-management could contradict with their roles in family or work, and with how they would like to present themselves in society.

Bury (1982)'s Biographical Disruption and Goffman (1959)'s Presentation of Self theories (Section 2.3.7) were influential in the synthesis of PLWL's narratives about the identity component. Key quotes of PLWL from the synthesised articles in relation to the stages of the identity component are presented in Appendix C5.

4.5.1 Disruption

Bury (1982) defined chronic conditions as 'disruptive experiences' in which the ways individuals conceptualise themselves and their identities in society were disrupted. Goffman (1959) explained how individuals had an 'ideal' version of themselves and

controlled their presentation via a theatre stage metaphor. At the front stage they would like to be identified as in their `ideals`, hence may act and look differently to guide others' perception of themselves. At the backstage they would be relaxed and would like to be in control of who could access that (Goffman, 1959). The narratives of PLWL from the synthesised articles presented that people could be reluctant to manage their condition, if they perceived self-management as conflicting with their `ideal` roles at work, within social contexts and in their families:

You know, I am a mother and a wife so it seems odd for me to make a big show of my arm. I feel much more comfortable when everyone is sleeping and I can take some quiet time to deal with it. But sometime, it is so late and I am very tired. So, I would tell myself, 'I'll do it tomorrow.' Then, I ended up not doing anything. (Fu, 2010)

Some explained that they stopped wearing their compression garments so not to bring attention to their affected limb.

My arm was massaged and wrapped several times a week. The swelling didn't go down. I was prescribed a glove and sleeve, which I wore religiously for quite a long time. But the appearance of my hand and constant comments about my sleeve became embarrassing to me. I quit wearing my sleeve. (Ridner et al., 2012)

They presented their desire to be perceived and felt like themselves before lymphoedema which they frequently described as `normal`:

I don't want to be easily identified as being sick. I am not sick! I am a survivor, I can make a full recovery. I don't want people to look at me funny, I don't want people to pity me. I just want to look and feel normal again. (Ridner et al., 2012)

4.5.2 Rethinking

PLWL expressed their desire and strategies to feel and look as themselves before lymphoedema, as well as their considerations of the limitations their condition brought.

Bury (1982) named that endeavour as `mobilisation of resources`. He explained that after

the diagnosis of the chronic condition, sustaining activities that were considered normal could become `a burden of conscious and deliberate action` (Bury, 1982).

PLWL frequently expressed that they wanted to hide their garments and affected limbs to avoid unpleasant comments and because they felt they would be criticised. Compression garments and bandages were perceived to be making lymphoedema more visible. Hence, PLWL looked for clothes and shoes to hide their lymphoedema, or did not wear their garments in public. Some PLWL explained that they did not mention their condition to their families, colleagues or friends because they wanted to be treated as normal and sustain their previous roles.

When conflicting with individuals' priorities in life, self-management could be perceived as a dilemma by PLWL. They explained their everyday strategies of adapting their self-management to make it feasible for their everyday life. They tried to find ways to maintain their swelling while not totally sacrificing what was important for them. One of the mentioned adaptations was "*wearing compression garments as much as possible*" (Fu, 2010). Even though that could be interpreted as not complying with self-management from a medical perspective, for PLWL that could be their best solution and was better than not wearing them at all. One of the participants in the study conducted by Fu (2010) expressed her concerns about being discriminated against at work and her everyday strategies to manage her lymphoedema despite that:

I don't want my boss to know that I am disabled by wearing the glove. But, once I start typing my arm becomes heavier and heavier and my hand becomes bigger and bigger. At the end of the day, I cannot even move my arm and curl my fingers. It is so distressing. All I can do during work is to hide the sleeve with a long-sleeve jacket, wear my glove during lunch break or, if the swelling becomes unbearable, go to bathroom and wear my glove for 10–15 minutes. (Fu, 2010)

Some of Fu (2010)'s participants described how they had to give-up their hobbies and change the ways they would handle everyday activities. They expressed that they had

chosen to `let go` what they would have preferred to do, to minimise their symptoms (Fu, 2010).

4.5.3 Re-invention

Some PLWL expressed how by re-inventing what they consider `normal` they were no longer considering lymphoedema as a limitation to their life.

I don't let it stop me doing things and basically I don't think about what I can't do. I just get on with what I can do. I don't dwell on what I can't do, but all in all really I don't let it affect me (McGrath, 2013)

Self-management was perceived as a strategy to live as normal as possible: “*If you can keep it managed, you can live a pretty well normal life*” (Bogan et al., 2007). When PLWL considered lymphoedema as a part of themselves, they could also stop being worried about hiding their lymphoedema. A participant of Lindquist et al. (2015) explained:

During the past year. I have learned to accept my arm and have begun to wear my short-sleeved shirts and blouses. Previously I did everything I could to hide the arm with long sleeved clothing in order to avoid all the curious looks and questions about what I had done to my arm. Mentally, it feels good now that I have come so far. That I do not worry about it any longer. It is as it is, best to just make the most of it, in other words take care of yourself and your arm. (Lindquist et al., 2015)

4.6 Support Network: Isolation to Collaboration

Human health is a social matter, not just an individual one (Bandura, 2004).

Support networks as a component of the lymphoedema self-management experience meant the extent of support that individuals receive from their network including, but not limited to, healthcare professionals, family, friends, colleagues and other people with lymphoedema.

The responses of PLWL from the synthesised articles presented the critical role of their support network in their journey. Bandura (2003)’s `Social Learning Theory` (Section

2.3.5) was influential in the synthesis of PLWL's narratives about the support network component. Key quotes of PLWL from the synthesised articles in relation to the stages of building a support network after lymphoedema are presented in Appendix C6.

4.6.1 Isolation

PLWL explained their frustration when healthcare professionals did not know about lymphoedema, underestimated its burden and failed to guide them for its management: *"I visited the doctor once a month and each time I told him there is something wrong, but he just said 'it will go away' ...nobody listens! I hate it when they say it will go away!"* (Maree and Beckmann, 2016). They described that lymphoedema was not taken as seriously as many other chronic conditions:

If you're in there for a heart condition or diabetes or something else has happened, and you have some other medical condition that has nothing to do with why you're there, you're immediately flagged for nutrition, for diabetic meals. Once you've filled out your admissions or your stuff like that, it just happens and then they all make sure. But when they see you've got lymphedema and you know, 'Oh. Yeah, and your arm looks like it's three times the size it should be.' It's just, 'Oh, okay.' And I'm like, 'No, it's really not okay.' (Ridner et al., 2016)

PLWL expressed their frustration when they felt their lymphoedema was not well understood by their families and friends. Rounds and Israel (1985) explored the changes in individuals' social networks while they were adjusting to chronic kidney disease. They explained that while the individuals were having difficulties in coping with their chronic condition, the composition of their social network could change significantly diminishing the support they received when it was most needed (Rounds and Israel, 1985).

PLWL in the synthesised articles explained how they felt misunderstood, leading them to avoid social occasions: *"People do not understand it! I try to explain to them, later I lock myself up in my room, because I am too tired of explaining"* (Maree and

Beckmann, 2016). One of the participants of Viehoff et al. (2015) expressed that she preferred to hide her condition even if that meant that she could not get support:

...I don't know how to explain it. Everybody would like to assist you but in some sort of way you live in a cocoon. You go your own way and you seclude yourself from them. There will be a moment in time that you will realize that you can't do it alone, but I am not at that point yet. (Viehoff et al., 2015)

4.6.2 Recognised

PLWL explained how they started to ask for help at home and work, because of the changes in their capabilities. Yet, for some, these brought concerns about losing independence and being a burden to others: *"I feel guilty about being the one who causes all of the worry, extra work, exhaustion, and boredom"* (Ridner et al., 2012).

I did not tell my children ... I thought they were nearly adolescent. Difficult age to handle and they are too sensitive... I didn't tell. I knew that if I said that, my husband absolutely would help me out ... I did not want to put more load on him ... well rather I felt sorry for my husband. (Tsuchiya et al., 2015)

One of the participants of Tsuchiya et al. (2015) expressed how she learnt to `identify supportive and non-supportive individuals` and revealed her lymphoedema selectively, she explained:

I only talked about [both breast cancer and arm problems related to lymphoedema] to close friends whom I spend most time with, but to the others, I did not say anything. They are not considerate and treat me as a normal [healthy] person. I don't hear a word of consideration from them, but it is necessary for me. (Tsuchiya et al., 2015)

4.6.3 Collaboration

Frank (2004) described chronic conditions as losing the `destination and map` of life and expressed how individuals re-construct a new map by telling the stories of their illnesses. The characteristics of their social network determined how individuals shared their stories and their journey. PLWL described their referral to a lymphoedema therapist

as a turning point not only because they could finally get answers to their questions, but also because support brought them hope and motivation to manage:

[the lymphoedema therapist] turned a lot of things around for me actually, made things more positive. I feel like I have the will and strength to continue and that my arm can be this good in the future too. (Karlsson et al., 2015)

Bandura (1977) in his Social Learning Theory emphasised the importance of ‘Verbal Persuasion’; someone telling us that we can succeed increases our belief about our ability to be successful. For PLWL, lymphoedema therapists were not only a source of physical therapy but also a medium that contributed to the increased hope and belief in one’s ability to manage lymphoedema.

The support network was not limited to the healthcare professionals, and individuals’ personal network was also shown to be important for managing a chronic condition. Rounds and Israel (1985) emphasised that no matter how strong the personal network of individuals were, these may not be able to meet the needs arising with a chronic condition. They suggested peer support to create new links, and enable the support from people who successfully made through their self-management journey (Rounds and Israel, 1985). Bandura (1977) defined the process of learning from the experience of others - named ‘vicarious experience’ - as one of the sources of self-efficacy. For PLWL peer support was expressed as one of the ways to learn tips about self-management, normalise having lymphoedema and feel connected: “*Knowing there were others that had the same problem and were going through the same type of struggle that I was made a big difference because I felt I wasn’t alone anymore*” (Bogan et al., 2007). One participant focused her frustration with her doctor into a desire to proactively educate others with lymphedema:

There are a lot of people here that have lymphedema, but they don’t know what it really is. They don’t have anywhere to go....I really need to get out and find these people and talk to them because I’m sure they’re living a nightmare, too. (Bogan et al., 2007)

4.7 Chapter Summary

Self-management was found to be a multidimensional journey for PLWL. In this chapter, this journey was described by synthesising the voices of PLWL with theoretical perspectives including behaviour change, adaptation and social-psychological models. Table 4-2 presents the six emergent components of the self-management experience, their definitions, theories that were influential in categorising these and the distinguished three stages for each component.

Table 4-2 Lymphoedema Self-management Experience: Summary of the results

Component & Definition		Main Influential Theories	Stage 1	Stage 2	Stage 3
COMPETENCE	feeling physically and intellectually capable of managing	<i>Skill Acquisition (Dreyfus and Dreyfus, 1980) – Section 2.3.1</i> <i>Experiential Learning Theory (Kolb et al., 2001) - Section 2.3.2</i> <i>Patient Health Engagement (Menichetti & Graffigna, 2016) - Section 2.3.9</i>	Novice: ‘I have some knowledge’	Proficient: ‘I have knowledge, skill and experience about self-management’	Expert: ‘I have experience in managing fluctuations and in a variety of situations. Can intuitively make self-management decisions’
	feeling responsible, motivated and in-control of self-managing	<i>Patient Activation (Hibbard et al., 2004) - Section 2.3.8</i> <i>Self-Determination (Ryan & Deci, 2000) - Section 2.3.4</i> <i>Self-Efficacy and Social Learning (Bandura, 1977) - Section 2.3.5</i>	Amotivated: ‘I can’t manage’ ‘I don’t have a role in managing’	Extrinsic: ‘I feel guilty if I don’t’ ‘I was told to do these’ ‘I’m afraid of the consequences’	Integrated: ‘Correlates with my goals’ ‘It is a part of my life’ ‘I’m in control’

HABIT	actual performed action and its habitualness	<i>Patient Activation (Hibbard et al., 2004) - Section 2.3.8</i> <i>Stages of Change (Prochaska & DiClemente, 1983) - Section 2.3.3</i> <i>Patient Health Engagement (Menichetti & Graffigna, 2016) - Section 2.3.9</i>	Intention: 'I'm considering it' 'I'm not sure if I can manage this'	Adhesion: 'I do what I was told' Experiential: 'I try them out'	Balanced: 'I manage my condition despite fluctuations' 'I have a normal life despite my condition'
PSYCHOLOGY	psychological state in relation the chronic condition	<i>Five Stages of Grief (Kübler-Ross & Kessler, 2005) - Section 2.3.6</i> <i>Patient Health Engagement (Menichetti & Graffigna, 2016) - Section 2.3.9</i>	Overwhelmed: 'I'm sad and angry about my condition' 'Lymphoedema is worse than cancer' 'Lymphoedema reminds cancer'	Reconsidering: 'I know my condition is permanent, but I still get upset when symptoms occur'	Coming to Terms with: 'I accept my condition and am positive about it. I get on with my life as normal as possible'
IDENTITY	adaptation to changing social roles and identities after the diagnosis	<i>Biographical Disruption (Bury, 1982) and Presentation of Self (Goffman, 1959) Section 2.3.7</i>	Disruption: 'I'm not normal anymore'	Reconsidering: 'I'm looking for ways to hide my condition, even if that limits me'	Re-inventing: 'My condition is a part of who I am'
SUPPORT NETWORK	support received from healthcare professional and social network	<i>Self-Efficacy and Social Learning (Bandura, 1977) - Section 2.3.5</i>	Isolation: 'I feel my condition is underestimated and I am criticised'	Recognized: 'I'm looking for ways to get more support'	Collaboration: 'I feel supported and connected'

The stages presented in Table 4-2 should not be considered as the phases that every person with lymphoedema experiences nor in the given order. Each component could progress or regress independently from the other components. People could move back or

forward, or they could skip stages among this journey. As emphasised by Bury (1982), change in symptoms and life events affect individuals' approach to their chronic condition and their journey:

A chronically ill person can make adaptations to life-style and still have access to periods of classic sick-role behaviour when such events as surgical intervention or sudden exacerbations of symptoms occur. (Bury, 1982)

The influential theories in the definition of each of the described six components are presented in Table 4-3. None of the investigated theories by itself was fully conveying the lymphoedema self-management experience, as expressed by PLWL in the synthesised articles. Each theory mentioned presented a different perspective to self-management and behaviour of people about their healthcare within their own theoretical context. Table 4-3 should not be perceived as the direct representation of the same phenomena by various theories. The table presents the influential theories in the definition of each of the six components. These components present the results of the thematic synthesis of the experience of PLWL as represented in the literature. One of the results of the synthesis was that the lymphoedema self-management experience was transitional and people were going through stages for each of the components. Some of the influential theories were transitional and some were partially describing a transition as noted in Table 4-3.

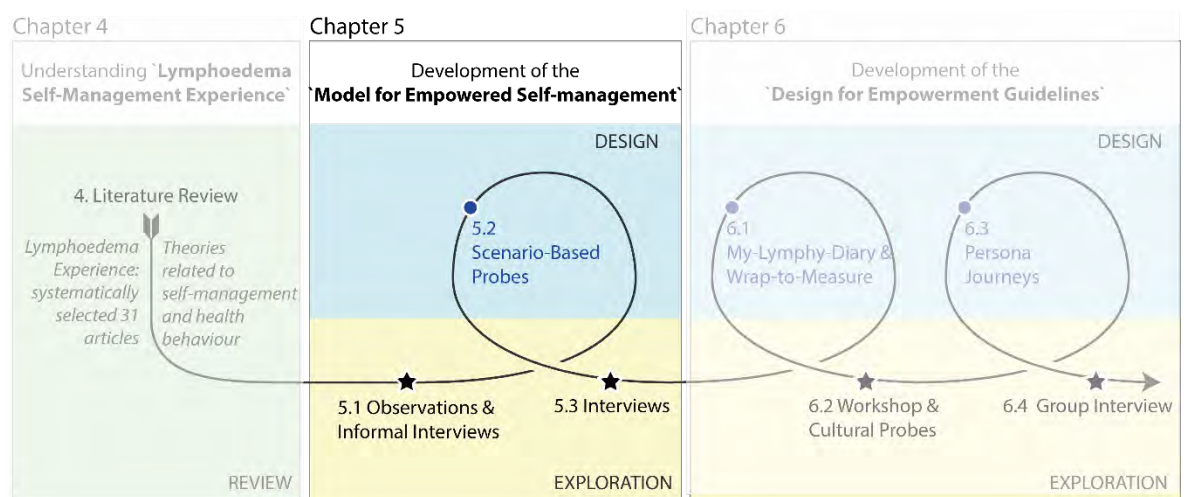
Table 4-3 Components of Lymphoedema Self-Management Journey in Relation to the Influential Theories

	Is it transiti onal?	Compete nce	Autonom y	Habit	Psycholog y	Identity	Support Network
Section 2.3.1 - Skill Acquisition Theory	Yes - for compet ence	Skill Acquisitio n	-	-	-	-	-
Section 2.3.2 - Experiential Learning	-	Experiential Learning			-		
Section 2.3.3 - Stages of Change	Yes	Stages of Change			-	-	-
Section 2.3.4 - Self Determination	Yes - only for Autono my	Competen ce	Autonomy		-	-	Relatednes s
Section 2.3.5 - Self Efficacy and Social Learning	-	Self-Efficacy: Performance Accomplishments, Verbal Persuasion			Emotional Arousal		Vicarious Experience + Verbal Persuasion
Section 2.3.6 - Five Stages of Grief	Yes - only for psychol ogy	-	-	-	Stages of Grief	-	-
Section 2.3.7 - Biographical Disruption	-	-	-	-	-	Biographi cal Disruptio n	-
Section 2.3.8 - Patient Activation (Hibbard et al., 2004)(Hibbard et al., 2004)	Yes	Knowledge	Belief and Motivati on	Skills	-	-	-
Section 2.3.9 - Patient Health Engagement	Yes	Cognitive: Health information seeking and use		Health behaviour change	Emotional Adjustmen t	-	-

In terms of their scope and approach, the models of Patient Health Engagement (Menichetti and Graffigna, 2016) and Patient Activation (Hibbard et al., 2004) were found to be the closest to the presented lymphoedema self-management experience. However, there were also differences. The Patient Activation Model (Hibbard et al., 2004) focused on the changes in the confidence and knowledge of patients for being active in their health and wellbeing. However, none of the social-psychological components (Psychology, Identity and Support Network) which were viewed as important by PLWL were mentioned in the Patient Activation model. In Patient Health Engagement (Menichetti and Graffigna, 2016) Model, the emotional adjustments after the diagnosis were elaborated. Yet, identity and social network components were not covered. Moreover, the experiential stage expressed by PLWL (section 4.1) was not mentioned. Instead, in Patient Health Engagement, an `adhesion` phase where patients were `formally adherent` was described. Yet, some PLWL expressed a different path, in which trials and errors for finding effective strategies and the minimum required for self-management was evident.

In this chapter, an understanding of the lymphoedema self-management experience was presented. This understanding built the foundation for the primary studies conducted with PLWL and contributed to the development of the scenario-based design probes. The presented components and stages were evaluated and iteratively revised through the primary studies. In the following Chapters 5 and 6, the results of the primary studies with PLWL and lymphoedema therapists are presented.

Chapter 5 Development of the `Model for Empowered Self-Management`



In Chapter 4, the results of a thematic synthesis of the systematically selected articles on lymphoedema experience was presented. This chapter presents the first part of the primary studies with PLWL, and the development of the `Model for Empowered Self-Management`. The following studies are presented in this chapter:

- Reflections on the observations and informal interviews (section 5.1),
- Design of the scenario-based probes for the interviews (Section 5.2),
- Results of the interviews with scenario-based probes conducted with PLWL (Section 5.3).

5.1 Reflections on the Observations & Informal Interviews

Observations and informal interviews provided an understanding of how PLWL experienced their appointments with lymphoedema therapists. Observations were

conducted in two different lymphoedema clinics and during three patient events. Informal interviews were undertaken with lymphoedema therapists to understand their experience and opinions about self-management during these visits. Three types of appointments were observed:

- 1) ***First assessment appointment:*** The lymphoedema therapist asked questions to the patient to get an understanding of the case and filled a digital form with their answers. The questions included the patient's health history, other related conditions, prior treatments related to lymphoedema and the lifestyle of the patient. The therapist made a physical examination by visually checking, pressing their thumb into the affected limb and pinching. The therapist explained that they would measure both limbs. The therapist marked the affected limb and the unaffected limb every four centimetres and measured these sections with a tape measure (see section 2.1.1 for more information about lymphoedema assessment). While measuring, the therapist noted these numbers on a printout table, and then entered these measurements into a computer software. The therapist informed the patient of the percentage calculated by the software. The percentage was expressed as the swelling of the affected limb compared to the unaffected limb. The therapist suggested wearing compression garments and prescribed one according to the measurements. The therapist asked the patient to arrange an appointment to check the fitting of the garment when it arrived.
- 2) ***Multi-Layer inelastic Lymphoedema Bandaging (MLLB) as a part of the intensive clinical therapy of lymphoedema:*** The lymphoedema therapist assessed the affected limb and explained the process and the expected duration of the treatment. The therapist used a bucket of water to wash the affected limb. They put a soft foam material around the limb and bandaged over that to achieve a graduated compression (see section 2.1.2 for more information about MLLB). While the therapist was

bandaging they talked about how the patient was doing overall. The therapists gave advice about strategies for self-management that would help to maintain the results after completion of the therapy, including keeping the limb clean and raised while seated.

3) ***Follow-up appointment:*** The lymphoedema therapist asked the patient how their lymphoedema had been over the previous six months. The therapist explained the aim of self-management as to lessen the impacts of lymphoedema on people's lifestyles. Ideally, PLWL would be self-managing so would only be seen at the clinic twice in a year for the prescription of their garments. Hence, patients had follow-up appointments every six months unless they encountered lymphoedema-related problems before that duration. Follow-up appointments were mainly focused on measuring the affected limb to detect any changes in the swelling and prescribing compression garments. The therapist measured the affected and un-affected limb in a similar manner to the first assessment appointment. The therapist stated the percentage of change in swelling since the previous measurements, and in-comparison to the un-affected limb. The next follow-up meeting in six months' time was scheduled as part of the appointment. The therapist told the patient to call the clinic if any problems occurred prior to the next appointment.

The field notes taken during the observations and informal interviews were considered from the perspective of the six main themes/components derived from the study presented in Chapter 4.

5.1.1 Competence: “*They didn’t tell me how to use this at all*”

Competence in the self-management journey means the extent to which individuals are feeling capable of managing. In the clinic, patients expressing low (novice stage) and high (expert stage) competence in self-management were observed. The support approaches of the therapists to these patients with different levels of competence were observed to be fundamentally different.

A male patient in his first-time assessment was not observed to be competent in managing his lymphoedema. He explained that he did not know how to manage and what to expect from self-management. He was prescribed compression garments previously by his GP (General Practitioner) but was never told how to wear them. He said, “*they didn’t tell me how to use this at all*”. The therapist demonstrated how to wear them and advised him to wear them every day to get better. The patient asked what ‘better’ meant in his case, and how much better his swelling could become. He inquired if he really needed to wear these every day and all the time. He explained that he was concerned about the flare-ups and pain, but the swelling itself was not worrying for him. The therapist proposed an action plan that consisted of trying the prescribed compression garment and checking how that affected his symptoms in the following appointment. In this case, the lack of competence of the patient seem to be addressed by the therapist through explanations, demonstrations, and by setting achievable expectations from the treatment and through an action plan.

In another instance, during a follow-up interview a patient was observed to be competent in self-managing. That was a female patient with lymphoedema after cancer treatment and she said she was wearing a compression bra. She explained finding the kinesiology straps very helpful and demonstrated its results to the therapist by pointing at the areas where she felt more comfortable. Kinesiology straps were recommended to the

patient by the therapist during a previous appointment and the patient explored different versions to find the approach that worked well for her swelling. The patient said that she did not use her arm garment anymore, because she did not have problems at that area. The therapist measured and prescribed another compression bra for the patient. The measurements reassured the patient by showing that her swelling had not changed since her last appointment. Unlike the previous example, this appointment focused on the self-management experience of the patient and her experiential knowledge. The patient was competent about managing her condition and showed the techniques she had found effective and non-effective. In this case, the source of information was not only the therapist, but also the patient. The patient was proactive and led the conversation. The therapist collaborated with the patient and reassured the self-management decisions made by the patient.

5.1.2 Autonomy: *“Do people really wear those [pointing to compression garments] every day?”*

Autonomy in the self-management journey means the extent of feeling responsible and motivated for managing. Lymphoedema therapists emphasised the importance of understanding the individuals’ motivation and ability for self-management, while planning the Complete Decongestive Therapy (CDT) and Multi-Layer inelastic Lymphoedema Bandaging (MLLB). MLLB involves weeks of intensive clinical treatment and after its completion, the patient should be self-managing and wearing their compression garments. If the patient does not self-manage, the improvements achieved by MLLB could be wasted and the lymphatic limb could go back to its previous swollen state very quickly. Therapists said that if there were no wounds or deformations, they did not always immediately start MLLB. In order to check whether the patient could tolerate the compression garments and

were motivated to use them, they would start the treatment by prescribing garments. Hence, starting with compression garments could allow the therapists and patients to experiment with self-management and assess the case better, before investing in the MLLB treatment.

Therapists explained that if the patients experience the benefits of self-management they tended to be more motivated. The measurements taken during the appointments was a way for the patients to check the effectiveness of their self-management. If the swelling was decreased or stabilised after six months, that could be a moment of celebration. Yet, disappointments were also observed. For instance, a patient in her 6th week of MLLB was expecting that her bandaging therapy would end on the day the observations were conducted. However, after the assessment the therapist advised to continue bandaging due to unhealed wounds. She expressed her frustration about bandages, and said “*What else can I do? I don’t have any other option, do I?*” and agreed to continue the treatment.

The therapists talked about the different approaches the patients had on self-management and self-monitoring. Some PLWL were keen to work hard to manage their lymphoedema and they were vigilant to their symptoms. Some of these even took copies of their clinical measurements and kept detailed records of the changes in their swelling over time. Yet, they explained that the majority of their patients were not interested in tracking their measurements. They said that for most of their patients hearing the change in percentage during their appointments with the therapists seem to be enough and preferred.

Patients could have preconceptions about the recommended self-management strategies. For instance, one male patient was having his first appointment in the clinic and did not wear compression garments before. Yet, he was surprised to hear the advice of the therapist, to wear the compression garments every day. He said, “*Do people really wear those [pointing to compression garments] every day?*”. Even before trying the garment on,

he objected to wear it every day. That lack of motivation was addressed by the therapist through explaining the benefits achieved by many other PLWL and the reasons for recommending to wear them every day.

Therapists mentioned that they had also found that some of the compression garments were faulty. That was reported as one of the reasons for PLWL to give up wearing their garments. Faulty garments could be ineffective in managing the swelling or even worsen the symptoms. The patients using such garments would be demotivated by experiencing exacerbated symptoms. The lymphoedema therapists said that the compression garments in their formulary had been tested at a specialist laboratory and more than half of the garments in the market failed to provide the compression levels that they claimed to achieve. In response, the therapists stopped prescribing such garments, and developed a revised formulary of compression garments indicating only the ones that were tested to be safe and effective. This was also described in a published paper (Thomas and Morgan, 2017).

5.1.3 Habit: “25% percent of self-management is wearing compression garments, the big portion 75% is changing lifestyle.”

Habit in the lymphoedema self-management journey means the actual performed action and the extent of this becoming a habit. Therapists expressed that the self-management routines of patients could become tacit in time and with increased expertise. Yet, novices could struggle with the everyday demands of managing lymphoedema. For instance, one male patient who was in his first appointment in the clinic reacted to the advice on wearing the compression garments every day. The therapist responded by suggesting a gradual increase to the garments-on days and durations. Therapists said that

wearing compression garments would become second nature in time, but that he did not have to start wearing them all the time instantly.

Therapists explained that lymphoedema self-management required patients to change their everyday routines. They explained that change in lifestyle needed a long-term investment and would not happen in a day. One emphasised the importance of change in lifestyle: *“25% percent of self-management is wearing compression garments, the big portion 75% is changing lifestyle”*. For example, lymphoedema specialists explained the importance of sleeping habits in self-management. Evidence suggested that many PLWL were sleeping on their sofas instead of beds, which was causing aggravation of the swelling. This could be because they fell asleep there, or because they had problems walking up the stairs to their bedrooms. To address this issue, the initial assessment included a question about the sleeping habits of the patients, and advice was given to elevate legs and sleep in a bed.

Lymphoedema therapists explained that even though academic studies were usually on breast-cancer related lymphoedema, there were increasing number of patients coming to clinics for other reasons including primary lymphoedema and non-cancer related secondary lymphoedema. They said that cancer patients might be more compliant in their self-management, and so may face fewer complications. Therapists said that it was not always possible to rely on patient accounts for understanding their adherence to self-management. They told that adherence could be manipulated by the patient, and that some patients who did not wear their compression garments in their everyday life would wear them just before their appointments to be seen as adherent. Therapists explained that they could identify such cases from the skin tone and the condition of the swelling.

5.1.4 Psychology: “Some patients call us only to have a chat”

Psychology in the self-management journey is how individuals think and feel about their condition. Lymphoedema therapists explained that there was a wide range of patients: from severe cases to mild ones; from non-mobile patients who could not wash their feet, to young and active individuals. However, the level of concern displayed by a PLWL did not always correlate with the severity of their symptoms. Therapists explained that people with complex issues may not see lymphoedema as the focus of their life, since they were coping with other conditions. Yet, there were people with mild oedema who could be more worried and obsessed about their condition compared to people with severe lymphoedema. Therapist explained that they would encourage their patients to perceive self-management as a part of their daily routine, but not as the centre of their life.

The therapists explained that they dealt with many phone calls from patients. Whilst some would need intervention (for example, if compression garments became loose, or swelling increased), others had no change in symptoms but were in need of reassurance or psychological support from the healthcare professional. One therapist said that “*some patients call us only to have a chat*”. They explained that managing lymphoedema could be more difficult psychologically for individuals who did not have an adequate support network.

5.1.5 Identity: “I don’t want to scare people in the swimming pool”

Identity in the self-management journey means the biographical adaptations after the chronic condition. During their observed appointments, patients mentioned some instances where lymphoedema influenced how they felt about themselves. The oedema and/or garments/bandages worn to manage the oedema could make lymphoedema a visible

condition. Such visibility of the condition could connote a disabled or sick role for some. For instance, one female patient explained that the bandages almost made her pain visible to others around her. In this case, the visibility of the condition was perceived as an advantage because it allowed others to empathise with her. In another instance, one male patient explained that he would appreciate it if there were a way to make his swelling better, so that he would not scare people in the swimming pool anymore. That remark implied the influence of the condition to his everyday life, and that he felt criticised by other people around him because of the way his condition looks.

5.1.6 Support Network: *“She [pointing his wife] is actually wearing it only once a week”*

Support network in the self-management journey meant the extent of support received from people including healthcare professionals, family and other people with lymphoedema. Patients mentioned the support of their families and friends during their appointments. For example, one of the patients expressed that the bandages allowed her to receive more support from her family. She said that, thanks to the bandages, her son started to visit her more often and was eager to stay longer. She described that even though she was already in pain previously, after the bandages, her son finally understood the everyday life burden of her condition. The sick role attained by the visibility of her condition was desirable for this patient, because that meant she could receive more support from her family.

On the contrary, for another patient the concern and attention of the family member was observed to be undesirable. The family member was with the patient during their appointment and complained about the non-compliance of the patient to the therapist. The patient was wearing her garments for the appointment and said she was doing well.

However, her husband contradicted with her and said “*she’s actually wearing it only once a week*”. In this case, the family member took an active role in reporting the actual self-management behaviour of the patient. The husband also said he was reminding the patient to wear the garment in everyday life. The active role played by the husband in this case did not seem to be desirable by the patient. Such discrepancies also implied how people could perceive successful self-management differently.

5.1.7 Summary

PLWL were observed during their appointments with their lymphoedema therapists and informal interviews were conducted with lymphoedema therapists. The field notes were presented as reflections. The observations were limited in their scope and duration and could not represent experiences in other lymphoedema clinics or for other PLWL. Still, these observations provided a first-hand understanding about how PLWL were experiencing their appointments with lymphoedema therapists. This was the first primary study conducted for this study and allowed familiarisation with lymphoedema experience.

Observations implied that the lymphoedema therapists could be delivering different support approaches depending on the needs and level of competence of their patients. During the appointments with the less competent patients, the therapists focused on hands-on demonstrations, explanations and examples. They set a clear action-plan for their patients. Whereas, during the consultations with more experienced patients, the therapists took a more passive role. The main source of information in such patient lead appointments were the lived experience of the patients, and their own goals and aspirations. This observation complemented the results of the literature review (Chapter 4) in showing the various stages PLWL could be in their self-management journeys. It was

observed that, the lymphoedema therapists adapted their role from `being the expert` when needed, to `allowing the patient to be the expert` for more experienced patients to facilitate their empowerment.

The other main observation was related to `compliance` with self-management. During the observations, even if the therapists were not directly asking whether the patient was compliant with the self-management regime, PLWL were observed to be conscious of being assessed. According to the Clinical Commissioning Policy (Carroll et al., 2015) about Lymphatic Venous Anastomosis (LVA) microsurgery for lymphoedema, one of the criteria for eligibility was patient's adherence to their self-management treatment plans. Awareness about such implications of being marked as `compliant` or `non-compliant` could have been influential for these PLWL, making some to hide if they were not adopting the therapist's advice. This was also in line with the comments of the lymphoedema therapists. This observation was influential in the selection of the following research methods conducted in this study. Participants were informed about the independence of the research from their healthcare services and the interviews were conducted at a facility independent from the clinic. The presence of other people in the room was also observed to influence the response of the PLWL. To decrease such influence and to be able gain an in-depth understanding of the lived experience of lymphoedema, one-on-one interviews were conducted. There were no questions concerning compliance with self-management regime.

Observations provided an understanding of the clinical treatments, appointments and therapist patient communications. However, one major drawback of this approach was the limited insights gained about the self-management experience of individuals. Self-management is carried out by PLWL themselves and at their homes in private settings. Another disadvantage of the clinical observations was the formal structure and time

limitations at the healthcare facilities, not allowing an in-depth exploration of the patient experience. Hence, the observations at the clinical settings were not extended. To explore the lived self-management experience, one-on-one interviews with PLWL and cultural probe studies were conducted. In these studies, design probes were used. In the following section, the development of the scenario-based probes for the interview study is described.

5.2 Design of the Scenario-Based Probes for the Interviews

In this section, the development of the scenario-based probes is presented. Initially, the design strategies to support self-management that were influential in the development of the scenario-based probes are described. Then, the design of these probes (the cards, scenario and persona) are explained.

5.2.1 Design Strategies to Support Self-Management

Design strategies to support the self-management experience of people living with chronic conditions were investigated. This investigation intended to identify opportunities to support the empowerment of PLWL, by designing products and systems. Six strategies were distinguished to address the barriers and facilitators of lymphoedema self-management (barriers and facilitators were listed in Table 4.1). These strategies are explained in the following sections: skill-development, goal-setting, self-monitoring, personalisation, peer support and collaborative professional support. Implementations of these strategies for chronic condition management in general and specifically for lymphoedema self-management are explained.

5.2.1.1 Skill-Development

Skill-development means the acquisition of skills for managing one's own condition and has been differentiated from traditional patient education. In patient education programs, usually information that is generic to the chronic condition is provided and focus is on common problems that have been identified by healthcare professionals. Lorig and Holman (2003) emphasised that people living with chronic conditions needed the skills to identify their own problems and make decisions to manage in changing circumstances at their homes. Bodenheimer et al. (2002) argued that programs for chronic conditions that are focusing on problem-solving and self-management skills were more effective compared to traditional provision of information. Lippa et al. (2008) investigated the decision-making processes of people living with diabetes. Their study showed that being able to declare knowledge about self-management was not enough to take action and concluded that patients required problem-solving skills which may be delivered through the use of experiential learning methods (Lippa et al., 2008). Lieberman (2012) investigated video games for learning diabetes self-management and explained how these provided a medium to practice problem-solving by simulating causes and effects.

Existing implementations of this design strategy in lymphoedema: Videos were developed for PLWL specifically to show how to do Simple Lymphatic Drainage Massage (SLD) and exercises. Thomas and Morgan (2017) explained the co-creation of videos with patients and their use in the education of PLWL. Fu et al. (2016) described an online system for PLWL after breast cancer treatment, which included exercise videos and daily self-management strategies. However, self-management skill-development in broader sense for problem-solving and decision-making were not evident in the existing systems.

5.2.1.2 Goal-Setting and Habit Building

Goal-setting means determining self-management goals, and habit building means the repetition of self-management to make it a habit. Goal-setting and habit building were common behaviour change approaches to encourage people, who have intentions for change, to take action. Locke and Latham (2002) explained that goal-setting was increasing individuals' performance by directing the attention to the required actions, by energizing people in performance, increasing their persistence and allowing them to discover knowledge related to these goals. In chronic conditions, collaboration of patients with healthcare professionals in setting goals and action plans were considered important in supporting self-management (Bodenheimer and Handley, 2009, Lenzen et al., 2015). Sniehotta et al. (2005) presented that their action planning intervention was effective in enhancing the rehabilitation of people. Fogg (2009) suggested gradually adding small behaviours to existing routines to build new habits. He emphasised the importance of 'triggers' for encouraging people to take action (Fogg, 2009).

Existing implementations of this design strategy in lymphoedema: A goal-setting and action planning intervention led by healthcare professionals was developed by McEwen et al. (2017) for PLWL after head-and-neck cancer treatment. Their participants reported that they found these aspects helpful and feasible for their self-management (McEwen et al., 2017). The web based intervention described by Fu et al. (2016a) incorporated a reminder (as a trigger to encourage action) for lymphoedema self-management.

5.2.1.3 Self-Monitoring

In chronic condition management, self-monitoring (also called 'self-tracking' and 'quantified-self') was described as patient's monitoring/recording of their symptoms, feelings or behaviours, and interpreting/analysing this information to adjust their self-

management, treatment or to seek professional advice (McBain et al., 2015a, Wilde and Garvin, 2007).

Wilde and Garvin (2007) in their review of the information and communications systems for chronic condition management showed that self-measurements of the body was the most widely used strategy among the reviewed 350 systems. Previously, self-monitoring interventions for chronic conditions were reported in mediums spanning from paper diaries (Lee et al., 2013a) to mobile devices (Mamykina et al., 2010, Aarhus et al., 2009) and wearable smart monitors (Phillips et al., 2018). Some of the uses of current wearable technologies in chronic conditions included physical activity monitoring, understanding the correlations of physical activities to the symptoms, monitoring the progression of the condition and promoting health behaviour change (Phillips et al., 2018). Previous studies asserted that self-monitoring increased awareness and understanding of self-management, facilitated control over one's chronic condition (Wilde and Garvin, 2007, Mamykina et al., 2010), and provided information about ways to adjust self-management and make informed decisions (Orji et al., 2018, Aarhus et al., 2009).

Research suggested many benefits potentially could be attained from self-monitoring, yet its previous applications also presented weaknesses. Patel et al. (2015) asserted that even though self-monitoring devices were primarily marketed for increasing the motivation of their users for behaviour change, their ability to create sustainable behaviour change was not known. It was discussed that such behaviour change could not be achieved by self-monitoring alone, and the need for complementary strategies was emphasised to attain genuine change (Patel et al., 2015, Orji et al., 2018). Orji et al. (2018) described the weaknesses of self-monitoring strategies as being boring, difficult and tedious, and having the risk of triggering obsession and depression. Moreover, Schüll (2016) asserted that, even though self-monitoring was built upon the rhetoric of

`empowerment`, giving control and responsibility to their users, data tracking could rather transfer that responsibility to technology. They could interpret the gathered data, and tell their users what to do by nudging them (Schüll, 2016). Hence, according to Schüll (2016), monitoring technologies if not designed well, could further contribute to keeping their users passive and disempowered.

The importance of considering the social implications of self-monitoring was also discussed. Self-monitoring technologies were criticised for overvaluing the data compared to what human body senses, and for creating an idealised “*responsible citizen*” who was supposed to self-monitor to achieve an optimised health (Schüll, 2016, Lupton, 2014, Lupton, 2019). Lupton (2014) underlined the growing discrimination towards people who did not have the skill or desire to self-monitor.

Existing implementations of this design strategy in lymphoedema: Self-monitoring technologies for lymphoedema included tracking circumferential measurements, pressure, volumetric change and subjective symptoms. Galiano-Castillo et al. (2014) developed and evaluated a software called E-Cuidate¹ for logging and tracking PLWL’s circumferential limb measurements, which included an option to share the data with therapists and other stakeholders. Fallahzadeh et al. (2015) developed a sensor-embedded cuff for continuous measurement of the circumference of the affected limb. The Kikuhime Telecare System (McLaren, Helmer, Horne, & Blanchonette, 2010) was used during training therapists for multilayer bandaging, to show how compression levels changed according to the application of the bandage. Li et al. (2016) developed an ultra-thin and flexible sensing system that could be worn with compression garments without adding extra thickness. Lette et al. (2007) described a device that used water displacement to monitor the change

¹ Cuidate is a Spanish word meaning `take good care of yourself`.

in limb volume, that could be used by PLWL at their homes. Ridner et al. (2014a) presented the use of bioimpedance for monitoring the percentage of fluid accumulation in the limb affected from lymphoedema. Fu et al. (2016a) explained a digital application for PLWL after breast cancer treatment including users' assessment and logging of their symptoms.

Self-monitoring was selected as one of the approaches for supporting lymphoedema self-management in this study. The approach showed potential for supporting and engaging patients in their self-management by facilitating awareness and understanding of the chronic condition. However, in order to achieve such benefits, careful consideration is needed in the design of the monitoring experience, the presentation of that data and their interpretation. As described by Ruckenstein and Pantzar (2015) self-monitored *“data are not a solution, but rather a starting point”*.

5.2.1.4 Personalisation

Personalisation means tailoring the provided support according to the specific needs of individuals. In 2019, `personalised care` was set as one of the five major goals by NHS as a part of a five year plan: *“People will get more control over their own health and more personalised care when they need it”* (2019). Coulter et al. (2015) conducted a systematic review of the personalised care planning interventions for chronic condition care. They underlined that the aim of personalised care was to plan the management according to the concerns and values of patients, instead of following standard management procedures (Coulter et al., 2015). They defined personalised care as *“a conversation, or series of conversations, between a patient and a clinician”* for coming to an agreement on the goals and plan of the chronic condition management (Coulter et al., 2015). Their review presented improvements on the patients' self-management capabilities

and their health status through personalised interventions when compared to regular care (Coulter et al., 2015). Other mediums of personalised care were also reported previously. Lorig et al. (2004) conducted a controlled randomized trial of a printed and mail-delivered self-management program particularly tailored to “*exact diagnosis, problems, symptoms, demographics, health status, medications, self-efficacy, and other personal features of the patient*” with their participants with arthritis. They presented improvement in function, disability and self-efficacy (Lorig et al., 2004). The authors asserted that a tailored program that was delivered via mail could be especially advantageous for participants who did not prefer attending sessions in groups (Lorig et al., 2004). Similarly, Nes et al. (2013) described the benefits of web based interventions which provided personalised feedback to people living with chronic conditions through collecting data.

Compared to one-size-fits-all solutions personalisation in healthcare discussed to have potential benefits, however, it also raised some concerns. Ruckenstein and Pantzar (2015) emphasised that patterns emerging from data were heavily depended on the addressed questions, the context and how these were interpreted. Moreover, Boyd and Crawford (2012) explained that personalisation through quantified data use correlations and predictions, while missing the in-depth comprehension of a case within its context. Checkland (2017) asserted that ‘personalised care’ had the risk to privilege ‘pushy’ people, and create a ‘responsible’ patient culture.

Existing implementations of this design strategy in lymphoedema: No evidence of products and systems providing personalised care for lymphoedema self-management was found from the literature search.

5.2.1.5 Peer Support

Peer support means the support provided by individuals with similar experiences. Peer support could potentially provide knowledge, motivation and inspiration for self-managing chronic conditions. Bandura (2003) asserted that observing the success of someone with similar experiences increased one's belief in their abilities, and their self-efficacy. Funnell (2009) discussed that mediating peer support among people living with chronic conditions could be an economical and effective way to provide the needed education and psychosocial support. Embuldeniya et al. (2013) showed that people with chronic conditions perceived the peer support interventions as changing their outlook, knowledge and behaviour, and empowering them. Lorig et al. (2001) evaluated a peer-led community self-management programme and showed decrease in participants' health distress and hospital visits. A systematic review found some evidence on the benefits of peer support groups for the empowerment of cancer patients (Ziegler et al., 2022). Funnell (2009) identified three ways of delivering peer-based support: face-to-face group, one-to-one peer support and digital peer platforms.

Existing implementations of this design strategy in lymphoedema: Numerous support groups and online platforms for PLWL were established. These were mostly initiated by PLWL themselves, still there were also some led by other organisations. Lindsay (2013) described the community-based social clinics called 'leg clubs' which aimed to bring patients with leg problems together to socialise. That was not specific to PLWL but included people affected from lymphoedema in their legs. Another example facilitating peer support among PLWL was described by Moffatt et al. (2019). They investigated the role of an educational camp with children and adolescents with lymphoedema (Moffatt et al., 2019).

5.2.1.6 Collaborative Professional Support

Collaborative professional support means the facilitation of the communication and shared decision-making between healthcare professionals and patients. Von Korff et al. (2002) identified collaboration between the healthcare professionals and patients and their families as one of the fundamental elements of effective management of chronic conditions. Bodenheimer et al. (2002) defined collaborative care as sharing responsibility in chronic condition management between patients and the professionals. Professionals (as experts about the disease) and patients (as experts of their own lives) working together for the goal of increased self-efficacy was asserted to improve the management of the condition (Bodenheimer et al., 2002). Tele-rehabilitation (also called `tele-care` and `tele-health`) was described as the remote delivery of healthcare services, and suggested as one of the ways to engage and empower patients in their self-management, especially for people with mobility issues (Brennan et al., 2009). Mamykina et al. (2010) and Aarhus et al. (2009) described their mobile applications for people living with diabetes, which provided online platforms for them to review and reflect upon their blood glucose values with their healthcare providers. These platforms allowed people with diabetes to communication and coordinate their care with their clinicians without leaving their homes (Mamykina et al., 2010, Aarhus et al., 2009). The review of self-management technologies conducted by Nunes et al. (2015) reported different levels of patient autonomy in such digital communication tools. For instance, the application evaluated by Nachman et al. (2010) transferred the data collected from the patient directly to the clinician, while Storni (2011) focused at enabling patients to reflect on their data themselves before their appointments.

Existing implementations of this design strategy in lymphoedema: Galiano-Castillo et al. (2014) described a tele-rehabilitation system to facilitate communications between PLWL

and their therapists remotely. This system was designed to help taking circumferential measurements and logging them to web-based software for PLWL after breast cancer treatment. The measurements were evaluated and found to be reliable compared to the measurements taken by lymphoedema therapists at the clinic (Galiano-Castillo et al., 2014). Faett et al. (2013) reported on another tele-rehabilitation system to teach self-management of lymphoedema to people with mobility issues.

5.2.2 Development of the Scenario-Based Probes

These six design strategies introduced in the previous section informed the development of the scenario-based probes. These probes consisted of 1) the cards describing the features that might facilitate the self-management experience, 2) the scenario explaining how these features might fit into everyday life of PLWL, and 3) the persona describing someone recently diagnosed with lymphoedema who might use these features. In this section the development of these scenario-based probes are presented.

5.2.2.1 The Cards

Informed by the literature review and observational studies, features as opportunities to support lymphoedema self-management were generated. Cards describing these features were developed as a part of the scenario-based probes. A list of these cards and their relation to the design strategies is shown in Table 5-1.

Table 5-1 List of Cards in Relation to the Design Strategies

	Cards of the Scenario-Based Probes	Design Strategies
1	Attachment to compression garment to monitor one or more of the following: signs of infection [cellulitis], pressure, circumference, temperature, activity, compression or garment on/off etc.	-Self-Monitoring
2	Reminder and feedback through an everyday object about one or some of the following: increase in circumference, signs of infection or garment on/off etc.	-Self-Monitoring -Goal-Setting and Habit Building

3	Advice and tips for self-managing lymphoedema personalised according to the preferences, diagnosis, stage and symptoms, delivered through digital user interfaces . These data were gathered through the responses of the `persona` while setting up her account and via her connected devices.	-Personalisation
4	Digital interface to monitor symptoms of lymphoedema such as appearance and size through comparing pictures	-Self-Monitoring
5	Peer support by being able to call someone with lymphoedema on phone	-Peer Support
6	Peer support by a digital social network and an online forum	-Peer Support
7	Peer support by having follow-up appointments in clinics with groups of other people with lymphoedema	-Peer Support
8	Goal-setting and monitoring progress such as decrease in circumference or increase in activity	-Goal-Setting and Habit Building
9	Advice and tips for self-managing lymphoedema personalised according to the preferences, diagnosis, stage and symptoms, delivered through mailed newsletters and booklets	-Personalisation
10	Calendar showing and reminding about the upcoming events about lymphoedema, support group meetings and appointments etc. This feature intended to be a reminder for habit building and also widen support networks by disseminating the events in the community.	-Goal-Setting and Habit Building -Peer Support
11	Sharing the self-monitored data such as pictures and changes in circumference and activity levels etc. with lymphoedema therapists during follow-up appointments	-Self-Monitoring -Collaborative Professional Support
12	3D scanning the limbs for prescribing compression garments by the lymphoedema therapists during appointments	-Collaborative Professional Support
13	Asking questions and sharing the self-monitored data such as pictures and changes in circumference and activity levels etc. with lymphoedema therapists , through tele-rehabilitation, online communication and video calls etc.	-Collaborative Professional Support
14	Feedback and reminder embedded to the compression garment providing guidance about when and how to self-manage	-Skill-development -Self-Monitoring -Goal-Setting and Habit Building
15	Live video with feedback providing guidance for doing lymphatic massage and exercise	-Skill-Development
16	Lymphatic massager providing feedback about the applied pressure	-Skill-Development

The cards were prepared for conducting a sorting activity with participants during the interviews. Icons and pictograms were included in the cards as shown in Figure 5-1, to make them easier to be recognised by the participant during the sorting activity.

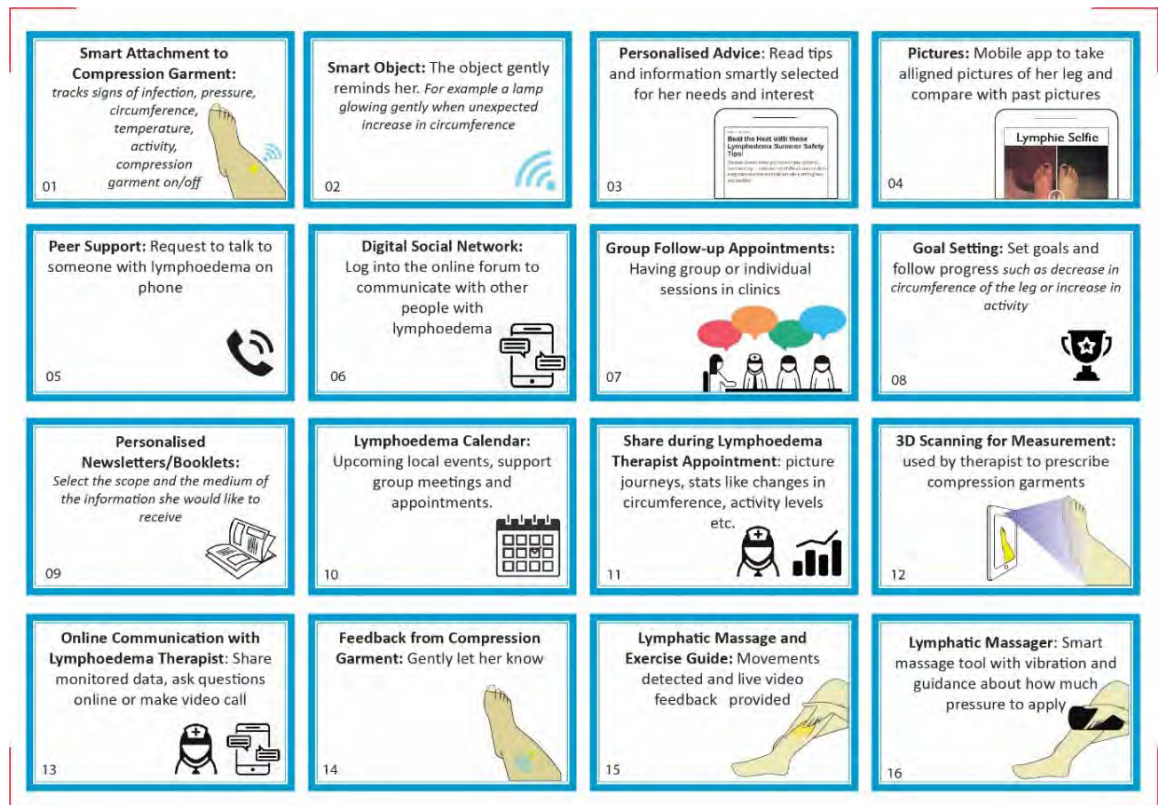


Figure 5-1 The 16 cards of the scenario-based probes

5.2.2.2 The Scenario

The scenario was written to address the barriers and facilitators for all the components of the self-management journey. Table 5-2 presents the barriers to and facilitators for self-management, in relation to the support strategies and the features in the scenario.

Table 5-2 Design strategies and the features in the scenario, in relation to the barriers and facilitators of lymphoedema self-management

Components	Barriers	Facilitators	Design Strategies	Features in the Scenario
Competence: Novice to expert	Instruction based delivery of information	Hands-on demonstrations and visual materials	Skill-Development	<ul style="list-style-type: none"> - Personalised Advice: Newsletters or booklets tailored for individuals (N: (Card Number) 3 and 9) - Communication of self-monitored data with therapists (N: 11 and 13) - Lymphatic massage and exercise guidance with feedback (N: 15 and 16)
	Conflicting or insufficient information	Being proactive in problem-solving and finding alternative sources of information	Collaborative Professional Support	
			Self-Monitoring	
			Personalisation	
Autonomy: External to Intrinsic	Lack of clear expectations from self-management	Having an understanding of the consequences of not doing self-management	Skill-Development	<ul style="list-style-type: none"> - Smart Attachment to Compression Garment: tracks signs of infection, pressure, circumference, temperature or activity etc. (N: 1) - Self-Monitoring appearance and size by comparing pictures (N: 4) - Goal-setting and goal monitoring (N: 8)
	Not being able to observe change despite practicing self-management	Seeing the benefits of self-management	Goal-Setting	
			Self-Monitoring	
			Personalisation	
Habit: Intention to Action	Lack of time, discipline and routine	Building Habits	Collaborative Professional Support	<ul style="list-style-type: none"> - Smart Reminder and Calendar (N: 2 and 10) - Goal-setting and goal monitoring (N: 8) - Feedback from compression garment (N: 14)
			Goal-Setting	
Psychology: Overwhelmed to Coming to Terms with	Overwhelmed about having the condition	Coming to terms with	Peer Support	<ul style="list-style-type: none"> - Communication with peers via phone, face-to-face and digital formats (N: 5 and 6) - Follow-up appointments together with other people with lymphoedema (N: 7)
			Collaborative Professional Support	
Identity: From Disruption to Re-invention	Self-management contradicting with preferred 'normal' identity	Adaptation of self-management strategies	Goal-Setting	<ul style="list-style-type: none"> - Communication with peers via phone, face-to-face and digital formats (N: 5 and 6) - Follow-up appointments together with other people with lymphoedema (N: 7)
			Personalisation	
			Peer Support	

				- Goal-setting and goal monitoring (N: 8)
Support Network: Towards Collaborative Care	Limited professional support and underestimation of the condition	Well-informed professional support	Peer Support Collaborative Professional Support	- Prescription of compression garments by 3D scanning at clinics (N: 12) - Communication of self-monitored data with therapists (N: 11 and 13)

The described features in the cards were narrated as a scenario. The scenario described a day with a (speculative) self-management support system. It started with explaining an on-boarding to the system (installing and setting up an account) and introduced the features. Examples were provided in the scenario to explain these features in a specific manner without constraining their scope. The first page of the scenario is shown in Figure 5-2 and the remaining four pages are provided in the Appendix D.

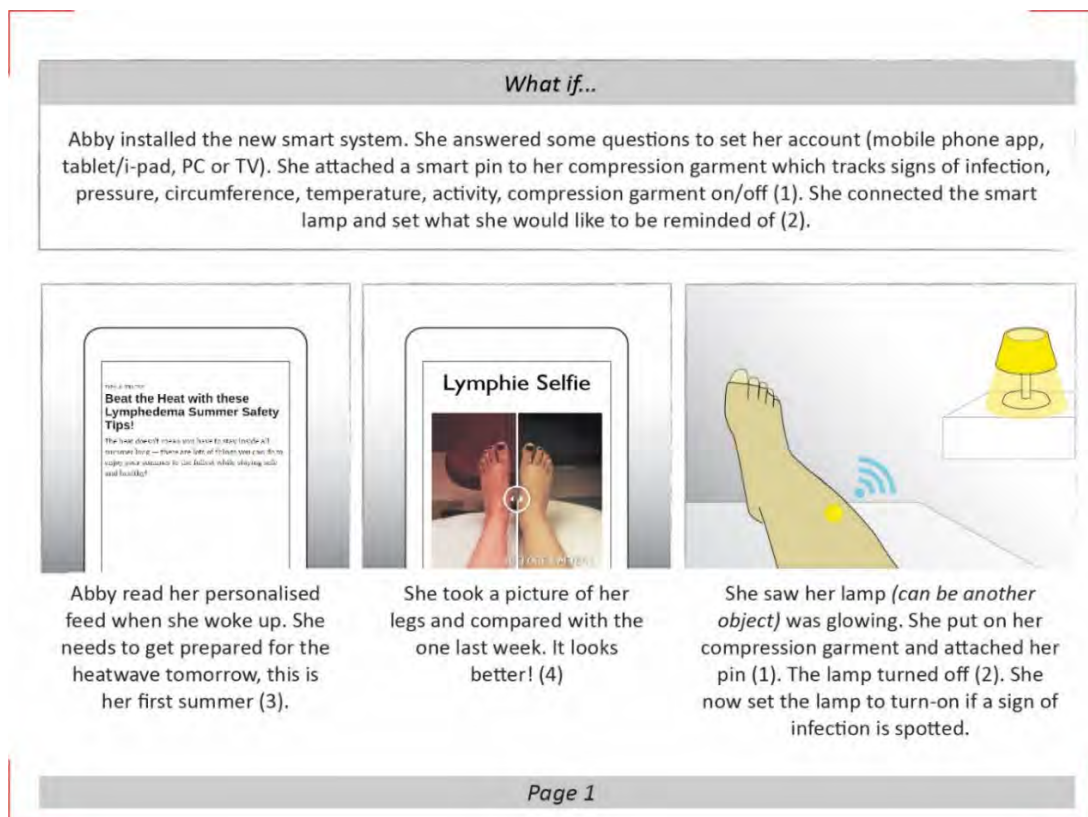


Figure 5-2 First page of the scenario

5.2.2.3 The Persona

The `persona` was the actor in the scenario (Figure 5-3). Lymphoedema experience was unique to individuals, and the persona did not intend to generalise or represent all PLWL. Rather the aim was to highlight the main barriers as described by PLWL at the beginning of their self-management journeys. The persona in this study aimed to:

- sensitise the participants with someone recently diagnosed with lymphoedema,
- make participants remember when they had their diagnosis, and
- engage them in the scenario as co-designers.

1 **Occupation:** Finance Project Analyst

2 Abby enjoys reading, gardening and hiking. She is keen on exploring new mobile apps for keeping in touch with her friends, shopping and tracking her exercises.

3 **Lymphoedema:** She noticed the swelling of her leg six months ago. It has been around a year since her cancer treatment. She had read about lymphoedema from the leaflets.

4 She is referred to a lymphoedema clinic. The lymphoedema therapist measured her leg and prescribed a compression garment. She explained how to do skin care and massage.

5 Abby put on her compression garment last week and did the massage as told. Still, she did not feel much of a difference. She is not sure if she is doing those properly. Even if she does not have her compression garment on, she only occasionally feels mild heaviness. However, today she woke up with pain in her leg and notice the increased swelling...

6

Name: Abby Miller
Age: 58
Family: Married. Has 2 daughters and 1 grandchild

What do you think might be helpful to her?

Figure 5-3 The persona of the scenario-based probes

Each attribute (annotated with numbers in Figure 5-3) of the persona was developed through the voices of PLWL as described in the literature (presented in Chapter 4). Figure 5-3 shows the persona with numbers linked to the attributes described below. These attributes were:

1) Lifestyle, family & work priorities: PLWL in the synthesised articles expressed the influence of their lifestyle, family and work life on their self-management routines. For example one of the participants in the study conducted by Jeffs et al. (2016) expressed: *“I’m struggling to find time to do it [my body massage] because I do full time job and I’ve got two teenage children, is like all hands on all the time”*. Hence, the persona was described as a working mother.

2) Hobbies and interests: PLWL described the activities and interests that they had to give up because of having lymphoedema. For example Fu (2010) explained: *“This made her consciously decide to ‘let go’ of a hobby that she had enjoyed since her childhood”*. Hence, the persona included hobbies such as gardening and hiking which could be perceived ‘risky’ after lymphoedema diagnosis. The persona was also described as ‘keen on exploring new mobile apps’ since some of the features in the scenario included such features.

3) Diagnosis and source of information: The persona was diagnosed with lymphoedema after cancer treatment (secondary lymphoedema). This was because the systematic inquiry of the literature (Chapter 4) evidenced more articles and information about secondary lymphoedema compared to primary lymphoedema. PLWL after cancer treatment explained the drawbacks of not knowing about lymphoedema prior to their treatment: *“I was not told about lymphedema before and I was not told about lymphedema after cancer treatment. When I started having swelling, I had no idea what it was because I never even heard about the word lymphedema”* (Fu and Rosedale, 2009). They explained that if they knew about the risk of lymphoedema previously, prior to their cancer treatment, their perception of this condition could be different. In the ‘persona’ description reading about lymphoedema from leaflets was

mentioned. This was intended to bring the questions about when and how the participants heard about lymphoedema in their diagnosis journey.

4) Difficulty following instructions: PLWL expressed that, even though they thought they had been clearly instructed on self-management, they could still find these difficult to implement at home. For example, one of the participants in Jeffs et al. (2016) study explained: *“I just find it very difficult to follow a sheet [instructions]. I'm more practical. I prefer someone to show me, and she has shown me but only once and I can't, I didn't take it in”*. Hence, the persona description did not include any hands-on demonstrations by the lymphoedema therapists. After the persona was referred to a lymphoedema clinic, her leg was measured, a compression garment was prescribed and how to do skin care and massage was explained to her.

5) Cannot see the benefits of self-management: PLWL explained that they were not always able to see the benefits of self-management. For some, that was causing doubts about the effectiveness of the management strategy and their confidence in practicing these. For instance one of the participants in the study conducted by Jeffs et al. (2016) explained: *“...though you know the professionals that are saying it works, but I can't quite believe it because it feels like you're doing absolutely nothing”*. Thus, the persona described that even though she wore her compression garment and did her massage `she did not feel much of a difference` and `she is not sure if she is doing those properly`.

6) Fluctuations: PLWL described that they had fluctuations in their swelling that they could not control. For instance one of the participants in the study conducted by Meiklejohn et al. (2013) explained: *“Lymphoedema seemed to be something like an incoming tide; ... there didn't seem to be anything you could do about it”*. Hence, the persona expressed such an occasion of swelling and pain

5.2.3 Summary

This section described the design of the scenario-based probes: the cards, scenario and persona. Design strategies to support self-management were identified to generate alternative ways to address the barriers to and facilitators of self-management. The scenario described 'how lymphoedema self-management might be supported'. Table 5-3 presents the design strategies in relation to the components of the self-management journey.

Table 5-3 Components of Self-Management Experience and Related Design Strategies

	DEFINITIONS	DESIGN STRATEGIES
COMPETENCE	<i>Novice to Expert:</i> Feeling physically and intellectually capable of managing	Skill-Development Self-Monitoring Personalisation Collaborative Professional Support
AUTONOMY	<i>External to Intrinsic:</i> Feeling responsible, motivated and in-control of self-managing	Skill-Development Goal-Setting Self-Monitoring Personalisation Collaborative Professional Support
HABIT	<i>Intention to Action:</i> Actual performed action and its habitualness	Goal-Setting Collaborative Professional Support
PSYCHOLOGY	<i>Overwhelmed to Coming to Terms with:</i> Psychological state in relation the chronic condition	Peer Support Collaborative Professional Support
IDENTITY	<i>Disruption to Re-invention:</i> Adaptation to changing social roles and identities after the diagnosis	Goal-Setting Personalisation Peer Support
SUPPORT NETWORK	<i>Isolation to Collaborative Care:</i> Support received from social network	Peer Support Collaborative Professional Support

5.3 Results of the Interview with Scenario-Based Probes

Results of the interviews with scenario-based probes are presented in two main parts (Table 5-4). The first section demonstrates the self-management experience of the participants with lymphoedema. The second section presents the experience of participants with the identified design strategies and their perceptions of these.

Table 5-4 Results of the Interviews: Main Themes

5.3.1 The Lymphoedema Self-Management Experience	5.3.2 Design Strategies to Support Self-Management
Competence	Skill-Development
Autonomy	Goal-Setting and Habit Building
Habit	Self-Monitoring
Psychology	Personalisation
Identity	Peer Support
Support Network	Collaborative Professional Support

5.3.1 Lymphoedema Self-Management Experience

The results validated the six components proposed in Chapter 4 and are presented below as categorised through these themes. The key quotes of the study participants that led to these components and their stages are provided in Appendix E.

5.3.1.1 Competence

COMPETENCE <i>The extent of feeling physically and intellectually capable of managing</i>		
Novice	Experiential	Expert
They told me to manage my condition by doing these. I am not sure how effective they are.	I explore new ways to better manage and observe possible triggers. It is trial and error. I am not fully confident about managing fluctuations.	I can manage my lymphoedema. I always look for new strategies to better manage.

Interview participants explained the challenges they had at the beginning of their lymphoedema self-management journeys. This was described as a stage where they received some information about self-management, but were having doubts about implementing these by themselves. For instance, Margaret explained: *“In the beginning you don't know if you're doing it right. Something you've never done before, and you have only two sessions [with lymphoedema therapists] in a year”*. Participants discussed that, despite thinking that they had learned how to self-manage while their lymphoedema therapists explained, when they started to try these at home, they realised the procedures were not always very clear to them. Elizabeth explained a misunderstanding she had about a particular type of compression garment that was new to her and said: *“No one showed me... you've got no idea how it would feel... If it can be demonstrated as well as explaining, then it won't be open to misinterpretation”*.

After gaining primary self-management skills, and with growing competence, self-management started to become an active experiential process for the participants. This experiential stage involved testing, observing and reflecting:

I do more things now... I say, well I'll try it. It's a matter of trial and error... keep trying different things... If my ankle swells, I try to wear my wraps. I try using the suction cup. I try to target specific areas. (Mary)

All participants described exploration of causes and effects, linking triggers (e.g. weather, diet) and their management regimes (e.g. compression, activity, elevation and massage) to the fluctuations in their swelling. Yet, even after participants gained some competence in managing, and an understanding of the triggers, they could still experience fluctuations. This could made them feel not being able to control their lymphoedema. Carol explained: *“But all of a sudden my right leg just started to swell for absolutely no reason. Because I was always careful with my skincare and looked after them, and that's when I got*

miserable”.

The expert stage in competence was about feeling competent in self-management, which was a result of experience and experimentation. Participants described their competence in making self-management decisions and the importance of being proactive in problem-solving. Laura explained: *“It’s an evolving condition and you need to evolve with it. You can keep it to that level but you should be one step over it. Why my leg is suddenly not responding to it? It is because...”*

5.3.1.2 Autonomy

AUTONOMY <i>The extent of feeling responsible and motivated for self-managing.</i>		
Amotivated	External and Introjected	Integrated
I am managing my condition because they told me to do so. I wish someone could do this for me.	I feel guilty if I do not manage my condition. I am doing these because I am afraid of the consequences.	I am managing my condition because it is important for me; it corresponds to my goals and is a part of my life.

All the study participants were keen on managing their lymphoedema at the time of the interviews. Yet, this was not always the case for some. Jennifer explained that she used to find it difficult to wear her compression garment and did not wear it for some time. She explained that one of the reasons was because her swelling was not too bad at the time and compression garments did not seem necessary. Participants also explained that, even if managing their lymphoedema was important for them, some days they needed extra effort to motivate themselves. Helen explained: *“Sometimes I wake up and I’m not in a mood to be dealing with my leg. Sometimes you’ve got to motivate yourself... Patients always are looking for very easy solutions”.*

Participants explained that they found sustaining self-management difficult in the long-term if they did not internalised the motivation and instead doing it because it was

recommended (external motivation). For instance, Carol explained that she was doing simple lymph drainage because she was told it would be good for her, but her doubts about its effectiveness led her to lose her motivation:

They say it [simple lymph drainage] is the best thing you can do, but I often wonder how effective it is to get fluid from legs. I don't know how effective it is... Sometimes I do religiously and sometimes I forget. I'm not as dedicated as I was at the beginning (Carol)

Participants frequently mentioned that they were self-managing because of being afraid of the progression of lymphoedema and feeling guilty if they did not. For instance, Carol explained: *"I have at least two legs to walk around on, but then that's another incentive to keep up with the self-management. If you let it go, you could end up in a wheel chair. That's a big motivation"*.

Participants frequently mentioned that seeing the benefits of self-management was helping them to sustain their motivation. Helen said: *"For me, it's to see your leg is responding... you know that motivates you to continue"*. Still, the benefits were not always achieved or observable. Mary described how she was seeking alternative strategies, despite not seeing the desired benefits from self-management: *"If you are slogging away and nothing is happening, and you start to think this is not working... you think, perhaps I'll try something else or what else can I do... That's why I try different things"*. To be able to continue during such times, it was important to have viable expectations from self-management, Laura explained:

Sometimes you feel like you are doing something endlessly and not seeing the results fast. Lymphoedema comes down to time.... You should have those goals to keep you motivated on the task and to remind you that this is going to take time. (Laura)

Participants explained how they internalised self-management and integrated the motivation as important for themselves. Self-management was important for the study participants for different reasons: Jennifer aimed to prevent cellulitis, Laura was keen on

having skinny legs again and Carol wanted to have same size legs. They defined their own criteria for success and took ownership in managing their lymphoedema. Sarah was proud of the results of her self-management: *“You have to work for it all the time. This [pointing at her leg] is amazing. You don't achieve it that easily”*.

5.3.1.3 Habit

HABIT <i>The extent of the actual practice of self-management and its routineness.</i>			
Intention I try to manage, but I (feel like) I cannot always do this.	Adhesion I strictly follow the self-management routine that was prescribed to me.	Balanced It is a part of my everyday life.	
	Experiential I explore the advised strategies to find effective ways to manage my condition.	I adapted my self-management to integrate it to my everyday life. I don't let my condition to take over my life nor to my symptoms to creep	I adapted my everyday life so that I can manage my condition.

Participants talked about times when, despite having an intention to manage, they could not because of reasons including lack of time and discipline. Lesley explained: *“If you're a busy person, and I was extremely busy until I retired... In those busy years, my self-management probably suffered a little bit”*.

In terms of self-management habits, two main approaches influenced by participants' personality traits and their lymphoedema journey were distinguished: adhesion and experiential. Some participants started by being `adherent` and diligently doing everything that they were advised to do. Margaret explained: *“Some people obviously leave it off, but I'm in the situation that I'm too frightened to leave it off. I keep it on constantly. Maybe I should put some cream on and take it off for a couple of hours”*. Others with an experiential approach tried out some of the strategies to find the minimum required self-management that would allow them to sustain their desired quality of life. For example, Mary explained how she stopped putting on compression garments to her left leg:

It's mostly in the right one... I don't wear the stocking to my left leg. I used to wear it for a long time. Then I tried not wearing and it's fine. I still have the stocking in case it swells, I will wear again. But it's fine. When it's really hot, it does a little bit because of the heat (Mary)

Participants described that they started by wearing compression garments, and then added various strategies to their self-management gradually: “you set out with always the compression and then you find the things to add-on” (Helen). They adapted their management strategies and lifestyles to build new habits:

How can I formulate my own programme?... It's about being able to assess and just forming a habit of knowing possible reasons of your up or down. But looking after yourself at the same time. (Elizabeth)

For the participants, everyday self-management decisions benefitted from their developing awareness about the triggers that worsened their lymphoedema. They were usually able to avoid these triggers. However, they did not always choose to avoid them. Some participants explained that they would undertake triggering activities despite knowing the possible consequences: “*I know, I'm going to do a lot today and will be in pain, but I don't mind*” (Lesley). They explained that they knew how to compensate for such effects within their everyday routines.

The balanced stage is achieved when self-management is integrated into daily life in a balanced, effective and feasible way. Participants mentioned the balance between self-management and life priorities frequently and the adaptations they made to their life and to their self-management routine to find a balance. These adaptations could sometimes prioritise ‘living as normally as possible’ or ‘living with a chronic condition’ by adapting everyday life to manage to the best extent. Sarah explained “*Try to do as much as you can, but not letting it taking over yourself. Being aware of it but still getting along with your life...It just doesn't stop me doing anything*”. Participants explained their self-management habits, and how that habituation made it easier for them. Laura explained: “*I came a long*

way along the years. Now, I don't even think about it. It's just like brushing my teeth, it's integrated into my daily habits. I find it very easy and barely think about it". Mary underlined the importance of finding exercises that she enjoyed: "Certain things work for some people. Some people like walking, swimming etc. You should enjoy it, because if you enjoy you'll do it more and will fit it in".

5.3.1.4 Psychology

PSYCHOLOGY <i>The extent of feelings and mental state towards the condition.</i>		
Overwhelmed I am sad and angry about my condition.	Reconsidering I know my condition is permanent, but I still get upset when symptoms increase or someone comments on my swollen limb.	Coming to terms with I get on with my life as normal as possible.
Hopeful Finally, I know what it is, and they said it could be managed.		I accept my condition. Thanks to my self-management, I can live the life I cherished.

Participants talked about feeling sad, angry and overwhelmed about their condition. Carol, who acquired lymphoedema after cancer treatment expressed negative emotions caused by insufficient communication of the risks of lymphoedema prior to her cancer treatment: "I still get angry about it. They have given me something that I didn't know about and deal with it for the rest of my life with disgusting stockings" (Carol). On the contrary, for the participants with primary lymphoedema, who suffered from lymphoedema symptoms for a long time without knowing why, a diagnosis brought hope about finally being able to manage.

The permanence of the condition was described as challenging to accept: "Still, it [self-management] is not a cure. It's up to us to come to terms with it, deal with it" (Elizabeth). Participants explained how lack of information and support made them feel:

I was struggling with it, because I didn't know anything about it. I was at sea. It was hard and I struggled. I was depressed. How I can let this thing to make me down? But I didn't have any back-up, any support. (Margaret)

Participants described that even after they acknowledged the permanence of their condition, an increase in symptoms or comments about their swollen limb could make them upset. Despite practicing self-management, experiencing increased symptoms was highlighted as a source of frustration: *“But all of a sudden my right leg just started to swell for absolutely no reason. Because I was always careful with my skincare and looked after them and that's when I got miserable” (Carol)*. Participants said that coming to terms with the permanence of the condition and the responsibility of managing it every day required time. Sarah said *“You’ve got to learn not to dwell on it too much. Try to do as much as you can. Not letting it taking over yourself. Being aware of it but still getting along with your life...”*. Mary explained that understanding the triggers and strategies to cope with these helped her to accept fluctuations:

It goes up and down. Even if it goes up, you have to be still positive, accepting that it can go up. Especially if it's particularly warm day or being on it too long... Sometimes you think you can keep going as you used to. It's accepting it and adapting and pacing yourself. You have to learn to pace yourself. You have to learn to read the signs when your body needs to rest, because if you don't rest you just make it get worse. (Mary)

5.3.1.5 Identity

IDENTITY		
<i>The extent of biographical state and feelings about oneself with the condition.</i>		
Disruption	Re-thinking:	Re-invention:
I am not normal anymore.	I am looking for ways to hide my condition, even if that limits me. I am not fully comfortable about having this condition.	I do not limit or change my life because of my condition. I do not let my condition to identify me, nor my symptoms to creep.
		My condition is a part of my identity. I prioritise managing my condition. I want others to know about my condition and self-management.

Some participants described their affected limb as `ugly`, `horrific` and `disgusting`. They explained that they did not feel `normal` because of their swollen limb, and were embarrassed about it. This identity `disruption` stage was passed for some of the participants, while for some others it continued. Some described that they were looking for ways to hide their swelling to be able to `fit in` or not to stand out. Lesley explained:

I can't tell you how embarrassed I am of my legs. For instance, I no longer go to swimming. I don't admit that to many people, but since you're doing research it's important, apart from no one will know it's me... I hide my legs because people stare, and that's horrible, but you can't change other people's lives. It's their problem, but I don't want it to be my problem, so I always wear long skirts and trousers... It does restrict me I can't dance, I can't go swimming. I mean, I can go but I don't... I know that it's ridiculous, I know that none will notice me and it won't be anybody I know... I just can't deal with it myself (Lesley)

Sarah said that she always wore her compression garments, apart from one day which was her daughter's wedding. She explained how she worked hard on her lymphoedema to be able to wear what she wanted on that special day:

It was a long time ago. I took a week off work and I stayed in the bed for 3 days, and then I didn't have the hosiery, but have the ordinary stockings... I stayed in the bed for three days to be able to wear proper shoes (Sarah)

Participants frequently expressed the difficulties they had in finding clothes and shoes.

That was not only because it was difficult to find the ones that fit physically, but also fitting their preferred identities. Jennifer explained: “*Also one of other challenges is to getting the clothes to fit. Getting garments to fit, to find trousers to fit. Getting fashionable clothing. Even though I'm sick I don't want to be totally old lady dressing*”.

The Re-invention phase was expressed as considering lymphoedema as a part of the individual's identity. Some participants preferred not to share their condition with others around them. Sarah explained “*I don't want to walk a room and people say, oh she's got lymphoedema. I don't want them to know, they don't need to know... I think that's how you*

sort of cope”. Elizabeth explained that “ensuring that you look good and feel good” and “ensuring that you're confident in your own body” was a part of self-management.

Other participants described how they were not allowing lymphoedema to limit their activities and clothes. They did not mind sharing their condition with other people. Helen compared her approach with the other PLWL she knew: “I’m posting my pictures with sandals and they are like ‘oh I would never do that’... they would be horrified about the idea... I would be going to beach. This is important”. Mary explained how she came to terms with how her leg looks:

Today I wear sandals. This is the first year I wear sandals and show my stocking. Because I was so conscious of it, I used to buy shoes that would cover up my legs, boots. I wouldn't let my feet to be seen. You've got to build up your confidence with it (Mary)

5.3.1.6 Support Network

SUPPORT NETWORK <i>The extent of support received while living with the chronic condition (including healthcare professionals, family and other people with lymphoedema etc.)</i>		
Isolation Nobody can help me; I feel alone and isolated with this condition.	Recognized I was given information and received tools for self-management.	Collaboration I feel supported and well connected. We work in collaboration with my healthcare professionals to better manage my condition.

Some participants reflected back to their past and described the times when they felt isolated and that they could not get the support they needed. Sarah described her experience prior to the development of lymphoedema services: “They discharged me and said that's it, there is nothing more they can do... there was no clinic to get the hosiery or anything like that. That went on for quite many years” (Sarah). Lesley explained how she felt while she was trying to find out what was happening to her legs, yet could not get a diagnosis:

I was so fed up with the lack of information and care. By care I mean that people caring about there being something wrong about my legs. I needed help... You wouldn't believe the number of doctors who I have to explain what the matter with my legs is. (Lesley)

Participants said that lymphoedema was usually underestimated and could only be understood by other PLWL. Sarah explained: *“It's really difficult to explain it [to others]. Some of them would say ‘just a little swelling’, wouldn't they?”*. Sarah revealed that most of her family did not know about her lymphoedema, because she preferred not to talk about it. Lesley explained that she preferred to hide her condition from many people around her.

The Recognised stage was expressed by the participants as the process of finding ways to build a support network. Sarah described how getting involved in a charity, going to conferences and support groups helped her to gain knowledge and confidence about self-management.

The Collaboration stage was described as feeling well supported and having the ability to work together with lymphoedema therapists to better manage the condition. Sarah underlined that *“the ideal is having very experienced practitioners”*. All participants frequently mentioned the benefits of meeting other PLWL: *“That's how you learn tips and tricks. See that you're not alone” (Carol)*. Hearing success stories of other PLWL were expressed to be helpful: *“You meet some people that inspire you. Sometimes it is like you see someone and you think I can do that” (Helen)*.

5.3.2 Design Approaches to Support Self-Management

This section presents participants' experience and their perceptions of the design strategies for self-management support. Participants gave their opinions about the presented scenario and altered the scenario, providing insights about how they perceived these design strategies. In the following sections, these are presented in six categories:

skill-development, goal-setting, self-monitoring, personalisation, peer support and collaborative professional support.

5.3.2.1 Skill-Development

Participants developed self-management skills primarily through the demonstrations of their lymphoedema therapists, through experience and by inquisitively searching alternative strategies (including online sources, conferences and support groups).

Participants described many occasions in which they had found useful tips and strategies to manage their lymphoedema from internet. Yet Jennifer explained that she perceived online information sources potentially inappropriate and dangerous for someone recently diagnosed with lymphoedema (at novice stage). Referring to the persona Jennifer explained: *“there is awful a lot of information that's wrong... I think, at this stage, only diagnosed for six months. I would say stay clear from the social network”* (Jennifer). Carol said that it was better to stay away from searching lymphoedema from internet, because it could show the worst cases of lymphoedema, which could be disheartening for the viewer.

Mary and Laura said that video feedback (referring to card number 15) could be helpful to learn the right techniques. Laura explained: *“It helps you to get the skills correct. [Named a game console brand] game that you can feel and see if that's the correct pressure and technique”*. Mary explained the difficulties she had in learning how to do the lymphatic massages:

I didn't know how much pressure to put on and I think I was putting too much pressure. you need to go very gently. But then when they tell you to do the manual drainage and pummelling, to soften the tissue to. SLD [simple lymph drainage] is gentle, very light MLD [manual lymph drainage] is very hard. You just need to show them the pressure (Mary)

Elizabeth underlined the importance of hands-on demonstrations: *“it was explained but not demonstrated, so you would forget it. No one showed me”*. She explained that she did not know how tight her compression wrap should be, because it was not demonstrated and the

changes in different times in the day was not mentioned to her. She perceived that videos would be similar and would not be good enough, because she still could not feel the correct tightness.

5.3.2.2 Goal-setting

Participants had previously set goals for keeping themselves active, and to do regular exercises. Jennifer described her goal to have certain number of steps per day:

Last night at quarter to ten... and I hadn't done the 10.000 steps... so walked backwards and forwards. Just because I didn't have the 10.000 steps. I got it to it, five steps over 10.000... I don't always succeed, but it makes me do it, it makes me walk, it makes me to think about it... Some people do it naturally. I'm not a natural walker, but this makes me do things, and motivates me. (Jennifer)

On the contrary, Helen was not interested in counting her steps and said *"I'm the wrong person to talk to about that smart stuff"*. She had used a pedometer to count her steps previously, but she found that experience very stressful. Her goal was to move for one hour every day and she preferred to do a variety of activities: *"It's much easier for me to say just one hour... 20 minutes with the dogs in the morning and... some swimming... you know if I do more that's fine"* (Helen). Carol said that she aimed to stay active and keep her weight down. Her goal was to go to swimming three times a week. Sarah had a flexible approach. She did not describe any specific goals, yet had strategies to keep herself active:

I'm quite active I don't sit. I'm always doing something. It's on my nature not to sit... They say exercise - well keeping active is exercise. I'm not sure if you actually did all those classes whether those would reduce your swelling. I don't know... [Have you tried them?] No, I didn't try them. I think, I do enough exercise. I think it's keeping active really. Whether you do exercise or you keep walking or gardening. That's the thing I enjoy (Sarah)

Laura said that setting viable goals was very important. She said that short-term goals were not feasible for lymphoedema, because instant changes were not seen. Yet, long-term goals were also not effective for her. Laura explained that a medium-term goal, such as a month, was ideal to see changes in lymphoedema:

Sometimes you feel like you are doing something endlessly and not seeing the results fast - lymphoedema comes down to time. It's not a fast thing to change. You should have those goals to keep you motivated on task and to remind you that this is going to take time ... I think it's very important to set goals, otherwise you can get very despondent with the treatment quickly because it's not working, you need to give it time (Laura)

Jennifer said that decrease in the circumferential measurements was not a goal for her, because she believed that her leg could not get much smaller than it was. The other reason was that she already knew how to decrease her swelling. She explained that wearing her stocking would decrease the circumference, and not wearing would increase it a little. However, Jennifer said that for the `persona` that might be different: *“since she [persona] is new to it, maybe she will do it. There might be a chance that she can really preserve the leg”*.

Participants said that they were setting goals because it was keeping them motivated and aware. Lesley explained: *“It [goal-setting] keeps you aware of what's expected. We tend to get ‘I get lymphoedema and I just get on with it’. Because there is nothing that's going to change my situation...”*. She explained a scenario where she would log in her expectations from self-management, and the system would remind her. On the contrary, Carol was not keen about the reminder feature and Laura said that reminders would irritate her: *“Personally I think that would annoy me. It's about maybe in the beginning... you don't need at the later stages... maybe at the beginning to make them more compliant”*.

5.3.2.3 Self-Monitoring

Participants' self-monitoring primarily relied on subjective measures including checking appearance, size, and visual clues in comparison to memory and sensations. Mary explained that *“You can feel it. It's like when you're feeling unwell, it's like an instinct”*. All the study participants were monitoring via various subjective measures. Participants

mentioned the extra work required for taking measurements as one of the reasons for their preference for subjective methods:

I know some patients they measure themselves every day. Can you imagine doing that on top of everything else? I have a more flexible approach and I would look and say `oh it looks ok` kind of perspective. (Helen)

Three of the participants described how they measured their limbs. They said that they were measuring fewer sections than their lymphoedema therapist did and were comparing those with their previous written records or from their memory.

I used to keep a record and I used to do it all the time. Now I just do it when I think about it. I can remember the measurements and I know the difference... I guess, I have been doing this for 12 years. (Carol)

Mary shared the pictures she had been taking of her leg and described them as a way to monitor her swelling. She liked the picture taking aspect in the scenario:

[Showing pictures] this is last Tuesday. When I had my operation before the operation just to compare. I've just thought, if I don't do this (taking pictures) I wouldn't have anything to compare. You can't see yourself in how other people see you. It went down quite quickly... (Mary)

On the contrary, Carol explained that she did not want to take pictures of her leg: “*I wouldn't want to take any pictures, it stresses me. I don't take pictures of it*”. Subjective and objective self-monitoring measures described by PLWL are listed in Table 5-5:

Table 5-5 Subjective and Objective Strategies to Self-monitoring Lymphoedema

Subjective	Local sensations (pain, heaviness), Overall body sensations & energy level (feeling unwell), Size and appearance (naked eye, pictures, fit of clothes/shoes, gauge with hand, compared to visual cues) Texture (feeling while creaming and massaging), Mobility & flexibility
Objective	Circumference tape measurements, Copies of the clinical measurements, Weight, Temperature during cellulitis, Marking the borders of the area during cellulitis

Some participants reported differences between the measurements taken by lymphoedema therapists and their subjective perception of their swelling: Mary explained that: *“I was so convinced that my leg was getting bigger the last time... They measured and said ‘no it is actually smaller’ but it’s got bigger in different areas”*. Participants described early sensations and their strategies to prevent increased symptoms during such times. Mary said that *“You have to learn to read the signs when your body needs to rest, because if you don’t rest you just make it get worse. Elevate your legs... Just make that time for yourself to rest”*. Participants described how they aimed to analyse the reasons of fluctuations in their swelling by self-monitoring. This was through subjective self-monitoring for some and objective for others, Elizabeth explained: *“I analyse the reasons why and what if I have done something different. If my measurements change after 6 or 8 months, well actually you have to do something about it”*. They explained how their preference in self-monitoring changed along their journey. Elizabeth initially self-monitored objectively for exploring triggers and prior sensations, followed by subjective measures when she became competent in distinguishing onsets and sensations. Still, even after individuals became experts in their own conditions, an ongoing need for monitoring in the long-term was emphasised:

The danger is you carry on with the same treatment for such a long time that you don’t realize that perhaps it’s getting worse. Sometimes the clinic can discharge you.... I wonder if those people will remain vigilant when they’re discharged.
(Sarah)

Stimulated by the presented scenario-based probes, some participants discussed the potential benefits of smart systems supporting objective self-monitoring:

For people who don’t know much about lymphoedema, it can help them to learn about their condition better. If you could say that it’s happening because of that, it can make you more aware of your body. Maybe in the future you don’t need that.
(Laura)

Yet, Carol highlighted concerns about being obsessed with measurements and obsolescence of such tracking devices:

I wonder if that would become obsessive... they [people using an activity tracker] are alright for a bit and you got fun with it. Then, it's either an obsession or sits in the drawer. I'll say, if there is this technology, it would be interesting to just to see what it does. But, I don't think I would like to be ruled by that for the rest of my life... You don't know how much your leg goes up and down in the course of the day, do you? By the time you get back, it could have gone down. If you're in the house and if it's flashing you could want to stay at home, don't you? (Carol)

The possible emotional drawback of seeing the increased measurements was another concern and a reason for preferring subjective measures:

It is really awful to measure your leg one day and you do it the next day and you're like 'oh my god is 1 cm bigger but I feel my leg's so much better today and visibly doesn't look bigger'. So it's bit of a mind game - if you start measuring your leg constantly, I don't think it's good for your psychology. It makes you obsessed with the wrong things. Don't focus on measurements, but how you're feeling and looking and if you're able to put shoes on. (Laura)

Lesley said that she could already feel the increase. She said that seeing the increase in her swelling would not necessarily change the way she would manage it:

If that [increase in circumference] happened, what are you going to do about it? If my leg swells, what am I going to do about it? They are already in a compression garment and I just get on with my life until perhaps I can sit and put my feet up. But I'll already know... (Lesley)

In response to the concept of tracking signs of cellulitis (card number 1), participants explained their perceptions of this infection. Participants without prior experience of cellulitis believed they would feel the symptoms: “*If you know your leg, and would know if you're creaming every day, you'd know if there is an infection*” (Carol). However, those who had experienced multiple instances of cellulitis explained that they did not always experience common symptoms such as redness, pain and temperature: “*No, you wouldn't necessarily feel the infection*” (Lesley). Helen explained that she eventually learned to distinguish the early signs of cellulitis. However, in her experience healthcare

professionals did not always recognise such patient-led experiential knowledge. Helen explained that the last time she had cellulitis, she recognised the onsets but was not admitted to the emergency clinic before showing all listed symptoms, despite she knew not having a temperature was usual for her: *“He said to me, ‘no temperature’... I said, ‘we’ll see each other in a couple of hours and you’ll see how you delayed my treatment’”* (Helen).

5.3.2.4 Personalisation

Jennifer and Lesley said that personalising the advice provided was a good idea because everybody’s lymphoedema was different. Laura underlined that the content and quality would determine her interest in such information: *“We can get flooded with too much information... getting lots of e-mails... if it’s not interesting I would not open it”* (Laura). Carol preferred general information and she said information sheets covered everything. She said it would be better to consult lymphoedema therapists for specific inquiries, especially when someone was recently diagnosed (at novice stage) as in the case of the ‘persona’. For Helen, personalisation would not be possible. She said that she would not be able to select what would be interesting to her. As an example, she mentioned what she had recently learned and said *“how would I know that, if I said I’m not interested in diet... if it’s too much personalised you would not get information that might be useful for you”*. Helen said that for lymphoedema, it was important to be inquisitive and open for new information, and know how to do your own research and solve problems.

Personalisation of the support according to the stage of the individual in their lymphoedema journey was perceived useful. Participants mentioned that people with lymphoedema just after diagnosis needed hands on demonstrations from lymphoedema therapists for learning cornerstones of self-management. Participants reflected back to their

experience, and said receiving too much information from their therapists or from online sources could be overwhelming at that stage. Mary said *“But there is so much at the beginning... it can get scary. When there is so much information, you don't take it in either”*. Yet, after the individuals start practicing these fundamentals, gradually introducing other management strategies was perceived to be needed. Elizabeth said *“I wasn't updated about what are the exercises I could have done. ... what I feel is I'm still doing the same technique that was told possible 20 years ago”*. Mary described the management strategies that she learned from online resources: *“I looked online yesterday if there are any types of other exercises... spreading the toes out, I didn't know that, nobody really told me to do that”*.

After building a certain self-management routine refreshing strategies, continuing to self-monitor and being open for new developments were expressed to be important. Sarah said *“the danger is you carry on with the same treatment for such a long time that you don't realise that perhaps it's getting worse”*. Laura explained: *“It's an evolving condition and you need to evolve with it”*.

5.3.2.5 Peer Support

All the participants were within a peer support community and were keen on the benefits of sharing experiences with other PLWL. Margaret described peer support as helpful to feel better psychologically: *“Listening to those people [support group] was therapeutic for me to sort my own problems”*. Mary said *“I think when you get together as a group that can motivate you. We've got a small group and we sort of motivate and help each other”*. Carol explained the self-management tips she learned from support groups. Laura explained the benefits of observing the self-management of other PLWL and added:

You just need to talk about it. Don't be afraid to share the ugly side of things. We can empathy... the minute you share that someone might come with solution you know, 'I had that too, have you tried that' (Laura)

Participants expressed different preferences about the medium of peer support.

Mary described the benefits of reaching wider peer communities from online platforms and the additional self-management tips they could find: *"Just go online. ... I looked online yesterday if there are any types of other exercises for ankle exercises... [shows a new exercise] I didn't know that, nobody really told me to do that"*. Meanwhile, others emphasised that information sources not controlled by healthcare professionals could be risky and should be avoided, especially by novices. For instance, Carol said that *"If you're first diagnosed, the information should be coming from clinic... because there is so much misinformation out there"*. Margaret underlined that peer support was helpful, but it should not be perceived as a substitute for the professional support of the lymphoedema therapists:

Still I need to talk to somebody with the knowledge.... They [other people with lymphoedema] just get experience. They are experiencing it as I'm experiencing it... You're talking to people like myself, but not professionals. That's not really good enough, is it? Because you I want to speak to someone who knows exactly what is going on. What I should be doing and what I shouldn't be doing. Listening to a group of people is nice, but that does not relate to what I'm going through, because they are all different (Margaret)

Laura explained the importance of seeing lymphoedema success stories and meeting these people: *"...by seeing how they independently do and manage... Speaking to someone who is feeling good about it would lift you up"*.

5.3.2.6 Collaborative Professional Support

The support of their lymphoedema therapist was fundamental for all the participants. Sarah explained the importance of the attitudes and experiences of the lymphoedema therapists: *"If you go to a very professional practitioner who really know lymphoedema. That makes a big difference, how they measure you how they talk to you is all important"*. Margaret expressed her desire to see lymphoedema therapists more

frequently: *“It's only twice a year and it's really not enough support. They provide you your garments. Long-time not to see anybody”*. Carol emphasised the risks of receiving misleading information from online sources and the importance of professional support especially at the beginning of their lymphoedema journey. Sarah raised her concerns for the future about losing the support of the lymphoedema therapists: *“but now they want to discharge patients. I wonder if those people will remain vigilant when they're discharged”* (Sarah). Carol explained that even though she was grateful for the lymphoedema services, she was also resentful about not being eligible for the LVA (Lymphatic Venous Anastomosis) surgery. For the participants living in UK, the surgery was only offered to PLWL with cellulitis history. Carol said if she was not managing well she would have cellulitis and be eligible for surgery, which made her feel punished for managing well:

I'm not a priority, because mine is minor and I'm compliant... They said you needed to have cellulitis to have it [surgery] but that comes to my better self-management. It's like being penalised. Should I pin my leg and get cellulitis? (Carol)

Participants described the changes in lymphoedema services that they had experienced over the years. Sarah explained that supplying compression garments became easier for her, since it started to be carried out within lymphoedema clinics instead of through pharmacies. Some of the changes to the lymphoedema services in UK influenced the participants with primary and secondary lymphoedema differently. Previously, participants with secondary lymphoedema after cancer treatment used to have access to lymphoedema clinics, while primary patients could not be admitted. The services becoming open for all PLWL allowed primary lymphoedema patients to finally access the support they needed locally, and perceived to be very beneficial. On the contrary for PLWL after cancer treatment, that change meant that they had to share the provided

support with many others, which decreased the time they had with their therapists. Carol explained:

...as cancer patients, we feel quite aggrieved. Because the system is just being flooded with primary patients. So now, they know about it, they come with huge complex cases. They are complex. We just feel the services are now just a measuring service... It's not like the same. (Carol)

Even though participants described the follow-up appointments with lymphoedema therapists very beneficial, most of them perceived their appointments as a measuring service, instead of the treatment they desired to have. For instance, Elizabeth said that “*No treatment was given. What else I could have done, I'll never know. I'm grateful to get the garments, but that was all*”. The participants emphasised the time constraints limiting the provided support in lymphoedema clinics. Carol explained:

I've always think that the measuring system in clinic is so ad-hoc. They start there and they start with a pen to mark and take measurements. Well I'm sure in the days of modern technology there should be a way to just zap like that and it measures your leg... They are very quick but they are later putting those numbers to the computer and that takes longer. (Carol)

Participants suggested methods to shorten the time needed for taking measurements in clinics, Helen said that “[3D scanning feature in the scenario, card number 12] *would really reduce the risk of having to redo your compression garments*”.

The scenario-based probes stimulated conversations about how participants perceived their self-monitored data. Laura explained that sharing such data with their lymphoedema therapist would be beneficial: “*It helps make you more active in your healthcare; you can have better dialogue with your healthcare*”. However, the three participants who had kept track of their circumference measurements perceived that information as not useful in their conversations with their therapists. Carol mentioned that she had not shared her measurement logs with her therapist at all and said: “*I let them measure and tell me*”. Elizabeth explained that she shared these with her lymphoedema

therapist occasionally, but perceived that as a personal instrument: *“it's more about me understanding why this picks and drops”*. Laura described her concerns about reliability of such technologies and how their lymphoedema therapist might perceive: *“First of all, my clinician would not be happy about that”*.

Lesley described her ideal lymphoedema consultation in a way that would complement her experiential learning and is collaborative:

I would like to know that all eventualities are talked through. We would try and understand and talk about why things don't work for me... I work hard trying to make my legs better, and then I need to know that I'm trying all the right things. (Lesley)

5.3.3 Summary and the ‘Model for Empowered Self-management’

This section presented the results of the interviews with scenario-based probes, with nine PLWL. The stage and components of the self-management experience described by the interview participants were in agreement with and widened the results of the review in Chapter 4. The interviews with PLWL provided an in-depth understanding of the lymphoedema self-management journey towards empowerment. These are summarised in the ‘Model for Empowered Self-management’ as shown in Table 5-6.

Six approaches to design support were distinguished from the literature as having potential to facilitate the self-management of PLWL. These approaches were influential in the development of the scenario-based probes. Participants’ interactions with these probes provided insights about their perceptions of the design strategies to support self-management. The persona (who was someone recently diagnosed with lymphoedema) and the scenario, contributed to participants’ reflections on the past, present and future of self-management. Hence, allowed to gain insights on the changing needs of PLWL while they progressed towards empowerment in their self-management (Table 5-7)

Table 5-6 Model for Empowered Self-Management







	NOVICE	EXPERIMENTAL	EMPOWERED
COMPETENCE 	They told me to manage my condition by doing these. I am not sure how effective they are.	I explore new ways to better manage and observe possible triggers. It is a trial and error. I am not fully confident about managing fluctuations.	I can manage my lymphoedema. I always look for new strategies to better manage.
AUTONOMY 	I am managing my condition because they told me to do so. I wish someone could do this for me.	I feel guilty if I do not manage my condition. I am doing these because I am afraid of the consequences.	I am managing my condition because it is important for me; it corresponds to my goals and is a part of my life.
HABIT 	I try to manage, but I (feel like) I cannot always do this.	I strictly follow the self-management routine that was prescribed to me. or I explore the advised strategies to find effective ways to manage my condition.	Self-management is a part of my everyday life. I adapted my self-management to integrate it to my everyday life. I don't let my condition to take over my life nor to my symptoms to creep or I adapted my everyday life so that I can manage my condition.
PSYCHOLOGICAL 	I am sad and angry about my condition. or Finally, I know what it is, and they said it could be managed.	I know my condition is permanent, but I still get upset when symptoms increase or someone comments on my swollen limb.	I get on with my life as normal as possible. or I accept my condition. Thanks to my self-management, I can live the life I cherished.
IDENTITY 	I am not normal anymore. I want to go back to my life before this condition.	I am looking for ways to hide my condition, even if that limits me. I am not fully comfortable about having this condition.	I do not limit or change my life because of my condition. I do not let my condition to identify me, nor my symptoms to creep. or My condition is a part of my identity. I prioritise managing my condition. I want others to know about my condition and self-management.
SUPPORT NETWORK 	Nobody helps me, I feel alone and isolated with this condition.	I was given information and received tools for self-management.	I feel supported and well connected. We work in collaboration with my healthcare professionals to better manage my condition.

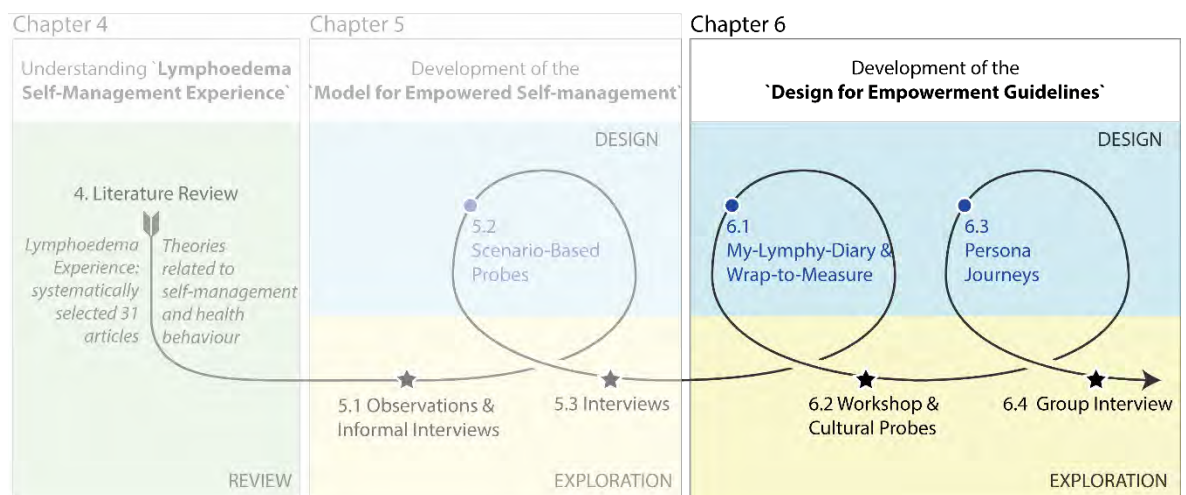
Table 5-7 Changing Support Needs towards Empowered Self-Management

	NOVICE	EXPERIMENTAL	EMPOWERED
SKILL-DEVELOPMENT	Hands-on demonstrations of cornerstones of self-management.	Experiential learning: testing, observing and reflecting on a variety of management strategies.	Evolving condition. Refreshing and expanding management strategies.
GOAL-SETTING	Setting viable expectations from self-management.	Setting goals for habit building. Gradually integrate self-management to everyday life.	Setting goals to maintain behaviour.
SELF-MONITORING	Developing awareness (subjective self-monitoring) to notice the changes in symptoms.	Self-monitoring (objective or subjective) to understanding the influence of the alternative management strategies and possible triggers.	Ongoing self-monitoring, because familiarity can make it difficult to recognize when strategies are not effective anymore.
PERSONALISATION	Less is more: Start with one essential management strategy. Do not flood with too much information and do not mention any not validated strategies.	Gradually add new and alternative management strategies and, explore possible triggers.	Update and refresh strategies with new developments.
PEER SUPPORT	Peer support for normalising the condition and psychological support.	Peer support for increased confidence and autonomy by sharing success stories and tips on management strategies and possible triggers.	Peer support to sustain motivation and be informed about the new developments.
COLLABORATIVE PROFESSIONAL SUPPORT	One-to-one and hands-on professional support.	Collaborative exploration of possible triggers and alternative strategies.	Patient led and continuous follow-up appointments to stay motivated and informed about managing lymphoedema.

5.4 Chapter Summary

This chapter presented the exploration of the self-management experience with PLWL. First, the result of the observations in lymphoedema clinics were presented. Next the development of the scenario-based probes was described. Finally, the results of the interviews with these probes conducted with PLWL were described. As a result, three main stages has been identified in the self-management journey (novice, experimental, empowered) and a `Model for Empowered Self-Management` has been presented. Design strategies to support this empowerment journey were explored, and utilised in the development of the scenario-based probed. Six design strategies were distinguished from the literature and the perceptions of the participants about these were investigated through interviews with scenario-based probes. Participants described that they needed different support strategies for self-management, depending on where they were at in their empowerment journeys. In the following chapter, a cultural probe study with PLWL and a group interview with lymphoedema therapists are presented. These studies further investigated the design strategies to facilitate empowered self-management.

Chapter 6 Development of the `Design for Empowerment Guidelines`



This chapter explores the design strategies to support empowered self-management.

Cultural probes with PLWL and group interview with lymphoedema professionals were conducted. In this chapter the development of the probes for these studies and their results were presented as follows:

- Design of the cultural probe: My-Lymphy-Diary and Wrap-to-Measure (section 6.1),
- Results of the cultural probe study with PLWL (Section 6.2),
- Design of the `Persona Journeys` for the interview with lymphoedema professionals (Section 6.3),
- Results of the group interview with lymphoedema professionals (Section 6.4).
- Design for Empowerment Guidelines (Section 6.5)

6.1 Design of the Cultural Probe: My-Lympho-Diary and Wrap-to-Measure

Serious illness is a loss of the `destination and map` that had previously guided the ill person's life: ill people have to learn `to think differently`. They learn by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared... telling stories about illness is to give voice to the body, so that the changed body can become one again familiar in these stories. (Frank, 2004)

In this section, the development of the cultural probes is presented. The cultural probe was composed of two main components: A reflective self-management journal called `My-Lympho-Diary` and, a low-tech tool for measuring the circumference of the certain sections of the limbs (arms or legs) called `Wrap-to-Measure` (Figure 6.1). My-Lympho-Diary is presented in Appendix F1.



Figure 6-1 My-Lympho-Diary (left) and Wrap-to-Measure (right)

The cultural probes were developed in two different versions for PLWL affected in their arm(s) or leg(s). The cover page of the probe explained the aim of the study, encouraged participants to amend the diary and reminded participants to consult their therapists (Figure 6.2).

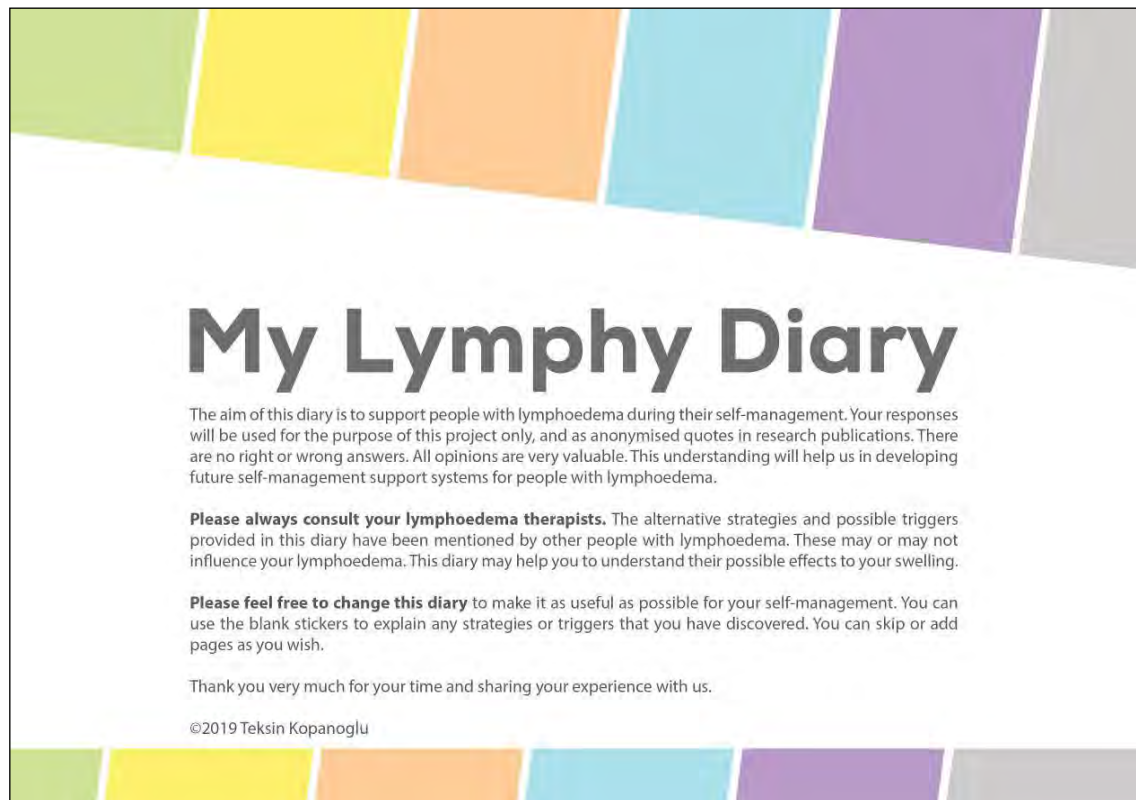


Figure 6-2 Cover page of My-Lympho-Diary

The pages of My-Lympho-Diary were composed of different probes for the particular needs of each component (section 6.1.2), but overall these pages shared a common structure as demonstrated in Figure 6.3. Pages started with a quote from the interview study and had probes to encourage reflection and experimentation. There were also pages of stickers listing alternative management strategies and possible triggers, aiming to further facilitate experiential learning.

The design of the cultural probe is explained in two sections. In the first section the influential theories and previous symptom diary examples in lymphoedema are explained. The second section describes the implementation of the self-management support strategies in the cultural probe and demonstrate the pages of My-Lympho-Diary.

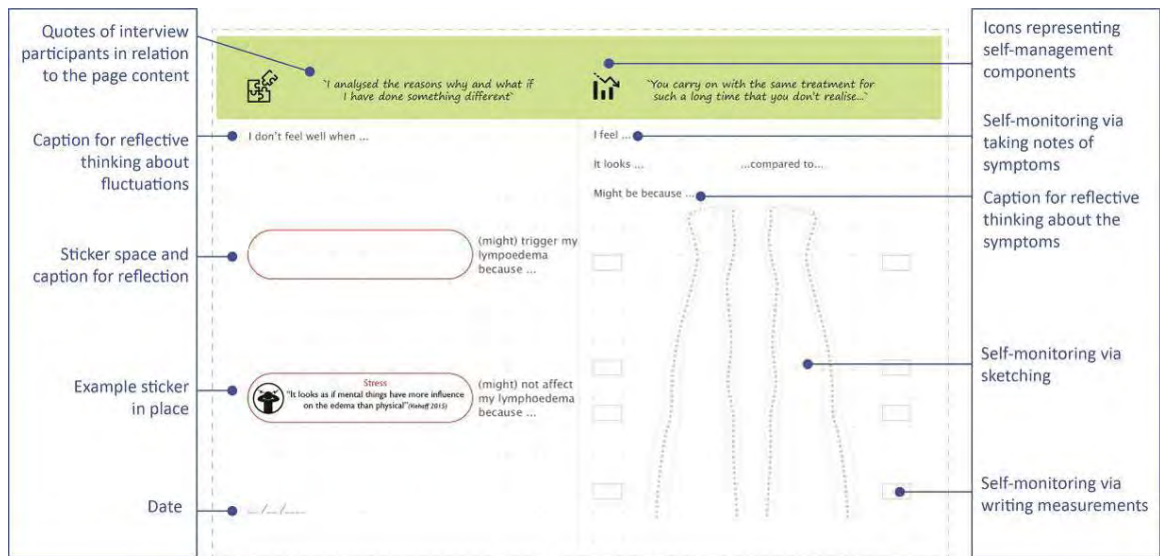


Figure 6-3 My-Lympho-Diary page structure

6.1.1 Developing the Cultural Probe: Influential Theories and Previous Symptom Diaries

The development of the cultural probe was guided by all the studies conducted up to this point that have been described in Chapter 4 and Chapter 5. The following were particularly influential in the design of the cultural probe and are further discussed in this section: 1) Kolb's experiential learning theory, 2) Bandura's Self Efficacy Theory, and 3) previous examples of lymphoedema symptom diaries.

Influence of Kolb's Experiential Learning Theory:

Learning is the process whereby knowledge is created through the transformation of experience. Knowledge results from the combination of grasping experience and transforming it. (Kolb, 1984)

As described in Chapter 5, participants with lymphoedema expressed learning to do self-management as an experiential process. Kolb (1984)'s experiential learning theory (introduced in section 2.3.2) has been recognised to have similarities with how study participants described learning to do self-management. Participants were testing, observing and reflecting possible triggers and management strategies. They were conducting active

experiments to contextualise the abstract self-management concepts explained to them. They were reflectively observing the results of these experiments.

The diary consisted of a variety of tools for facilitating participants' experiential learning by encouraging reflective observations and active experimentations. To ensure appropriateness for people with different learning styles, a combination of tools enabling "*feeling, thinking, reflecting, and acting*" were implemented as suggested by (Kolb, 1984). Figure 6.4 shows some of the pages of My-Lymphy-Diary in relation to Kolb's four main learning styles: diverging, accommodating, assimilating and converging. For instance, the pre-defined stickers developed to facilitate participants to "think" about possible triggers and alternative strategies. The stickers aimed both "assimilating" and "converging" learning styles. The caption in relation to these stickers [(might) trigger my lymphoedema because...] intended to facilitate:

- 1) "Reflection" about participants' past experiences,
- 2) "Acting" by encouraging the observation or testing of these triggers and strategies.

Influence of Bandura (1977)'s Self-Efficacy Theory: Bandura (1977)'s Social Learning Theory was introduced in section 2.3.5. According to Bandura (1977) self-efficacy (capacity or power to achieve a desired effect) was influenced from observations of how others perform the behaviour. If someone saw others succeed by following certain behaviours, they were more likely to perform these. Bandura (1977) called that 'vicarious experience'. 'Social persuasion' was another source of self-efficacy according to Bandura (1977). Encouragement received from others helped people to develop their efficacy and focus on achieving results. Consequently, in the cultural probe, quotes from other PLWL explaining how certain management strategies worked for them (vicarious experience) and

their encouraging quotes about coping with lymphoedema (social persuasion) were included in the cultural probe.

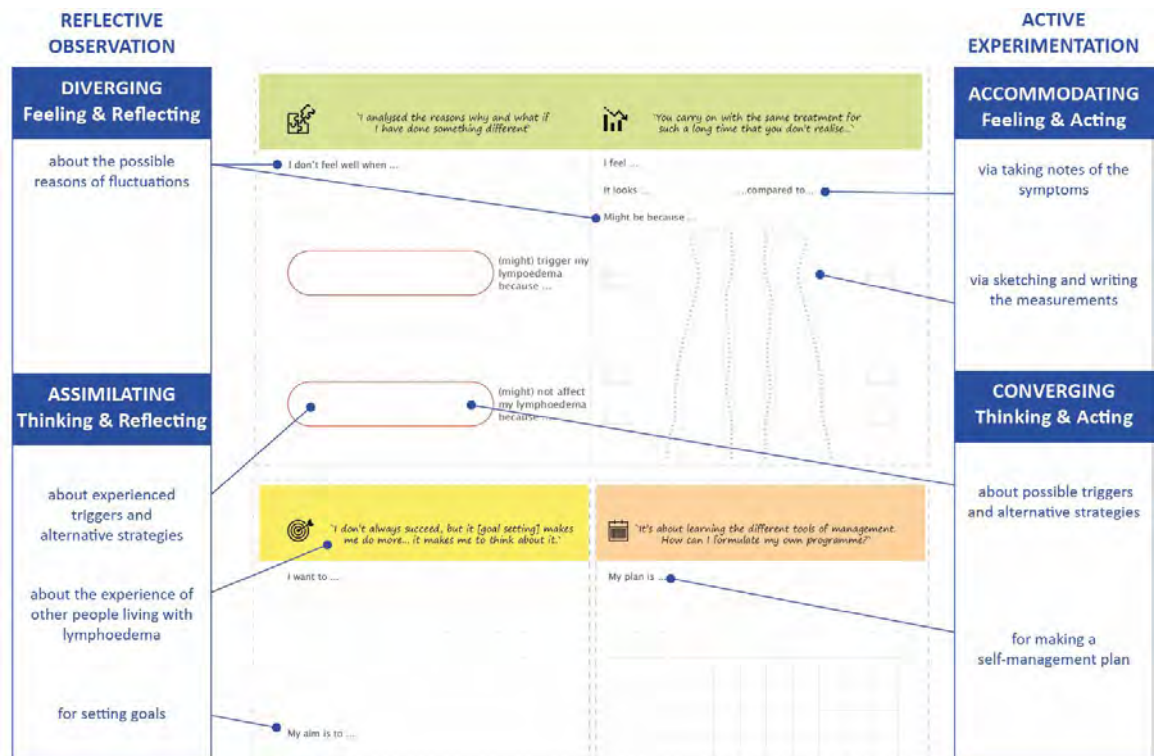


Figure 6-4 The Tools of My-Lymphy-Diary in Relation to Kolb's learning styles

Symptom Diaries in Lymphoedema: Symptom diaries were commonly encouraged for the management of chronic conditions, and research into their benefits was discussed previously (Lee et al., 2013a, Wright et al., 2003, Ong and Jinks, 2006). However, there was no advice on the use of symptom diaries for lymphoedema within the official guidance documents (Moffatt, 2006, NLP, 2019). Still, evidence about the use of symptom diaries by PLWL was revealed during the interviews, and through research among the active patient advocates as published in social media. Some compression garment companies published and provided booklets for PLWL to record their measurements. In this section, the use of symptom diaries by one of the interview participants (Elizabeth) and one lymphoedema patient advocate (Alexa) are presented. The development of the cultural probe was influenced from their symptom diaries and their usage of these diaries.

Among the nine interview participants, three of them described measuring their limbs and occasionally taking notes, yet only Elizabeth reported keeping a symptom diary. She said, she obtained “a measurement book with guidance of marks on a leg” (Figure 6.5). She reported keeping a record of both legs to check the difference. She measured “the ankle part, the calf below the knee and around the growing area”. In addition to this diary, she also asked for copies of the measurements taken by the lymphoedema therapists during her follow-up appointments. Elizabeth said she stopped using this diary around four years ago and started to keep a record of her weight instead. She said that after her surgery she realised that when her weight was creeping up, so did her affected leg. Elizabeth was keeping a record of her weight once or twice a day on a digital spread sheet at the time when interviews were conducted.

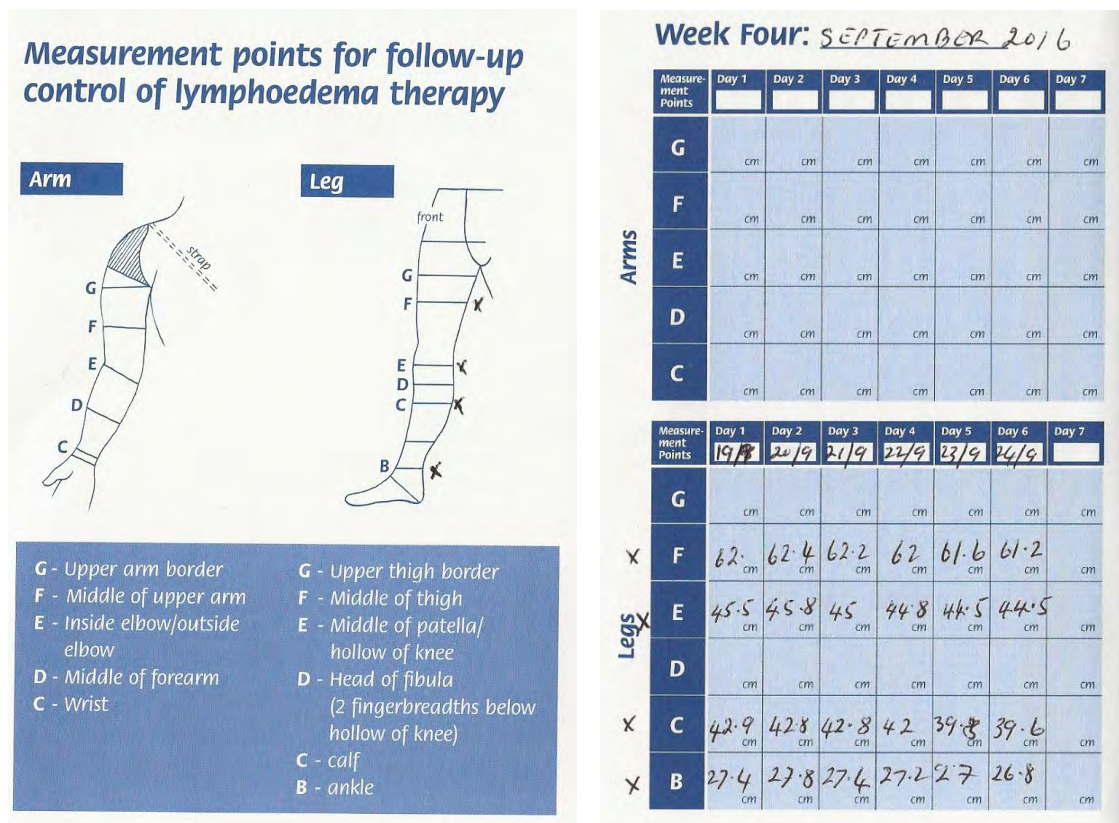


Figure 6-5 Lymphoedema Measurement Diary of Elizabeth (Booklet published by JOBST)

Alexa was also maintaining a lymphoedema symptom diary. She has been writing about lymphoedema and her experience “*to educate, connect, and support lymphedema patients and advocates across the globe*” (Ercolano, 2020). Alexa was diagnosed with lymphoedema at the age of 14 and started treatment a few years after that. She got compression garments and was taught how to perform manual lymph drainage along with the other strategies about living with the condition. However, she said she was not compliant with her treatment for years. She said, eventually she realized that she needed to take her lymphedema more seriously and began to wear her garments regularly. She explained that now she was trying to change her approach to her lymphoedema:

I’m trying to find ways to hold myself accountable for my health and be more mindful of not just my treatment, but how the treatment makes me feel. ALEXA

Alexa described that she had recently got into bullet journaling to track other habits and routines. She decided to use that approach to track her lymphoedema too. She said she adapted the layout from a lymphoedema diary booklet that she previously had, which was published by a compression garment company (Figure 6-6). Alexa explained her experience with the diary as logging what she already knew about, rather than finding out a new trigger. Still, she found keeping the diary useful to understand more about her fluctuations:

I’ve only tracked my symptoms a few times so I haven’t discovered any patterns or triggers that I’m not already aware of, but it’s been helpful to see how my measurements fluctuate and to consider the possible correlations. I’d definitely like to make my “lymphedema logging” a more regular thing, and want to experiment with tracking other metrics like weight, diet, and exercise. Like a lot of lymphedema treatment, it’s a bit of trial-and-error to see what works best. ALEXA

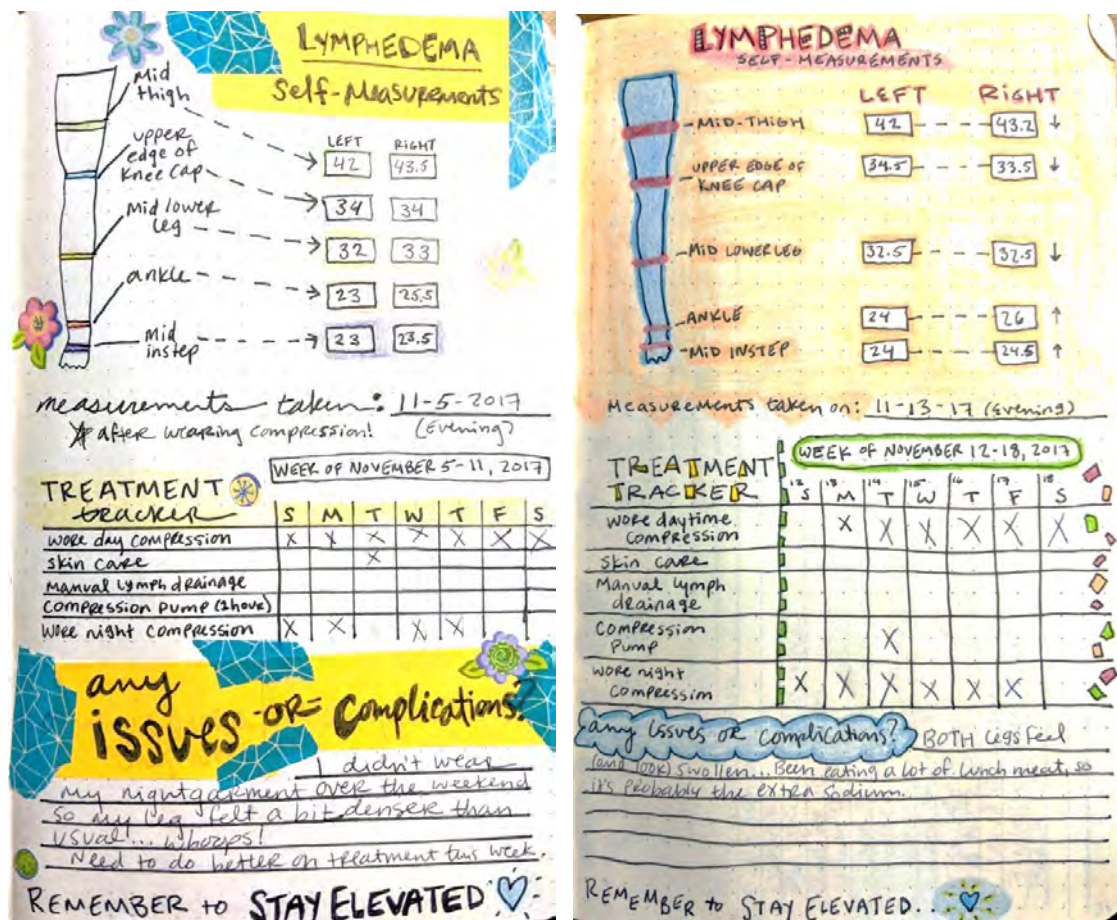


Figure 6-6 Lymphoedema Symptom Diary of Alexa

Alexa wrote an inspirational quote for herself on the diary pages: “remember to stay elevated”. She drew a weekly treatment tracker and noted the self-management strategies she had done. Alexa wrote about how her leg felt during the week under the section ‘any issues or complications’. Alexa sketched, coloured and added stickers to her diary. She explained that the act of creating this diary was meditative. For her, keeping a diary was a way to make self-management more engaging:

Drawing up the pages and coloring them has proved to be a somewhat meditative exercise in itself, and allows me to engage with my treatment in a creative and fun way. Some patients may be overwhelmed by the task of journaling or tracking, but I think for those driven by data or visuals like myself, it can be a very useful tool.
ALEXA

Elizabeth and Alexa had very different approaches to symptom tracking. Elizabeth used her measurement book as is and on a regular basis. Alexa personalized her symptom tracking diary, and used it only a few times to reflect on the progress. While for Elizabeth, symptom tracking was for “*forming a habit of knowing possible reasons of you're up or down*”, for Alexa it was for making self-management more engaging.

In the cultural probe, opportunities to use the diary for both of these purposes were accommodated. Sections to write down measurements, sketch, and use stickers were designed. To facilitate the exploration of the fluctuations, predefined captions were written such as “....might make my lymphoedema better because...”. The pages had quotes of interview participants. These quotes aimed to 1) inspire the user as in Alexa’s diary by showing what other PLWL says, and 2) provide guidance about ways to use the page as in Elizabeth’s diary.

6.1.2 Design Strategies in the Cultural Probe

In the following sections, the implementation of the design strategies for supporting self-management through the Cultural Probe is explained (design strategies were introduced in section 5.2.1).

Skill-Development:

It's about being able to assess and just forming a habit of knowing possible reasons of you're up or down, and looking after yourself at the same time. ELIZABETH

The diary intended to facilitate self-management skills for making well-informed day-to-day decisions. As explained in the previous section, experiential learning was influential in designing the cultural probe as a learning tool. Hence, beyond tracking and logging what happened (‘feeling, thinking and reflecting’), the diary included probes for the users to ‘act’, experiment and reflect (Figure 6.7).

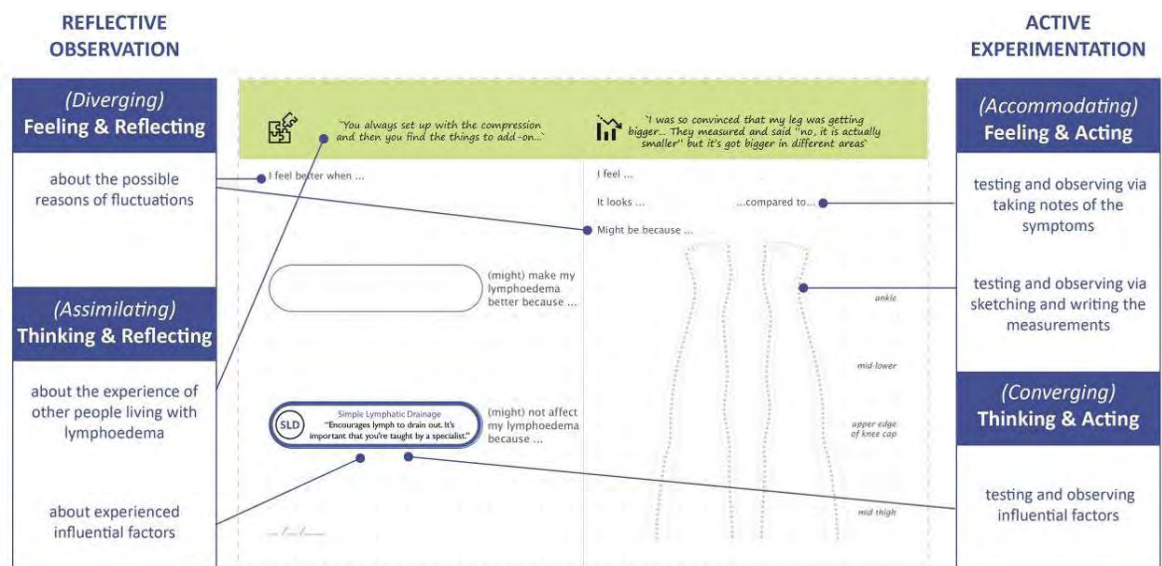


Figure 6-7 Implementation of the Skill-development Strategy of My-Lymphy-Diary explained

Stickers were developed to present a variety of possible triggers and alternative strategies to the participants. These stickers included the experiences of other PLWL from their voices (Appendix F1). The stickers aimed to encourage the participants to: 1) 'think and reflect' upon the strategies and triggers that they had experienced, and 2) 'feel and act' by testing and observing new strategies and possible triggers.

Goal-Setting:

Goals to keep you motivated on tasks and to remind you that this is going to take time... otherwise you can get very despondent with the treatment quickly... You need to give it time. LAURA

A goal-setting approach was implemented by providing probes to encourage 1) 'feeling, thinking and reflecting' on management strategies and possible triggers [I feel better when...might be because...], 2) 'thinking and reflecting' about the wants and desires of the individuals [I want to...], 3) 'thinking and acting' to set and implement goals [My aim is to...] (Figure 6-8).

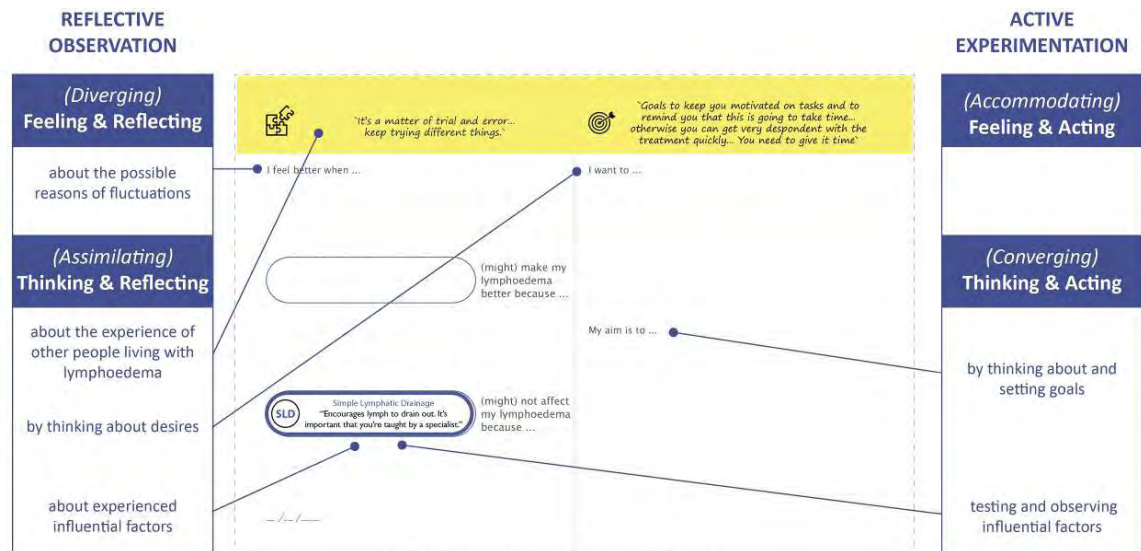


Figure 6-8 Implementation of Goal-Setting Strategy of My-Lymphy-Diary explained

In order to further explore the desires of the participants, a page prompting them to `think and reflect` on the future of the compression garments were included. Participants were asked to explain their magic compression garments and what they wished they had.

Building self-management habits and routines was also intended to be encouraged with the cultural probe. This was implemented by providing probes to prompt 1) `feeling, thinking and reflecting` on management strategies and possible triggers [I feel better when...might be because...], 2) `thinking and reflecting` by thinking about future and building a program [My plan is...].

Self-Monitoring:

It goes up and down. Even if it goes up you have to be still positive. Accepting that it can go up. Especially if it's particularly warm day or you've been on it too long.
MARY

Self-monitoring strategy was implemented through the design of My-Lymphy-Diary and Wrap-to-Measure.

My-Lymphy-Diary: Tools for both subjective and objective self-monitoring were provided. These intended to facilitate recording and reflecting upon lymphoedema symptoms as shown in Figure 6-9, and listed below:

1) Reflective Observations: `feeling, thinking and reflecting`:

- Management strategies and possible triggers [I feel better when...might be because...],
- Self-monitoring experience [I do/don't monitor my swelling because...],
- Self-monitoring preferences [I prefer/don't like because...].

2) Active Experimentations: `feeling, thinking and acting`

- Taking circumferential measurements (Wrap-to-Measure) and writing these down (My-Lympho-Diary),
- Taking notes of the symptoms by referring feelings [I feel...] and appearance [It looks...],
- Sketching the affected limb on the diary,
- Testing and observing the effects of influential factors,
- Testing and observing the effects of alternative ways of self-monitoring.

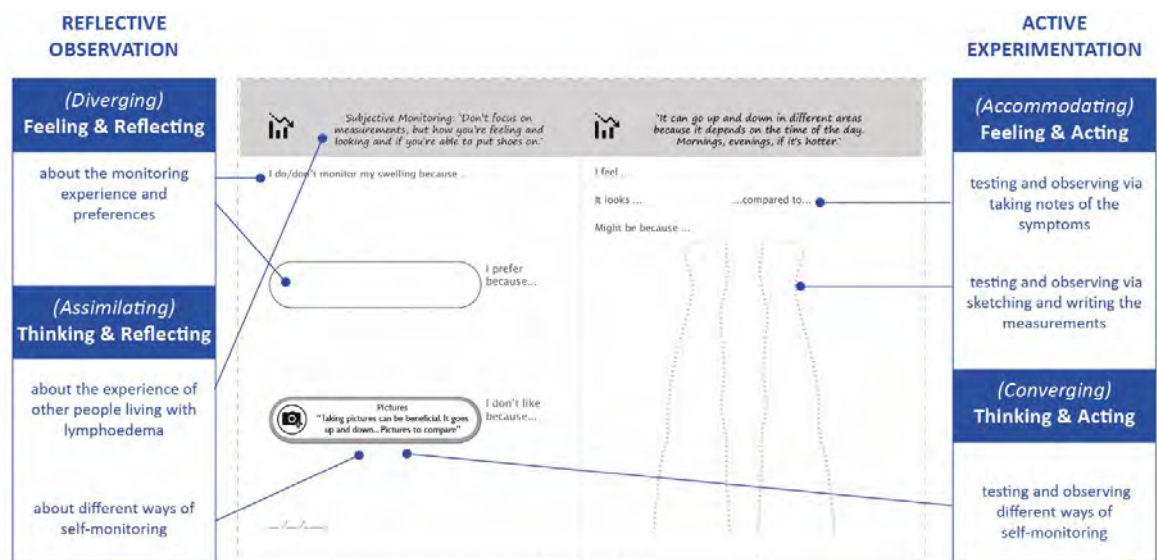


Figure 6-9 Self-Monitoring Approach of My-Lympho-Diary Explained

Previous lymphoedema symptom diaries presented the limb (arm or leg) drawing from an external point-of-view (side view). That point-of-view was also used in compression-garment order forms and was appropriate for lymphoedema therapists' viewpoint. In order to emphasize the cultural probe as a personal tool for self-management, the drawing of the limbs was presented from the point-of-view of the person living with lymphoedema. At the end of the diary, participants' opinion about these options were sought.

Wrap-to-Measure: Wrap-to-Measure is a measuring tool to monitor the changes in circumference of particular segments of arms or legs. Participants were invited to a

workshop in which they made their own Wrap-to-Measure. During the workshop, a step-by-step process of making a Wrap-to-Measure was shared with the participants (Figure 6-10). Prior to the workshop, prototypes were made to create and test the instructions. Several versions of Wrap-to-Measures were made to try different materials and create examples, for the participants to observe these before starting to make their own.

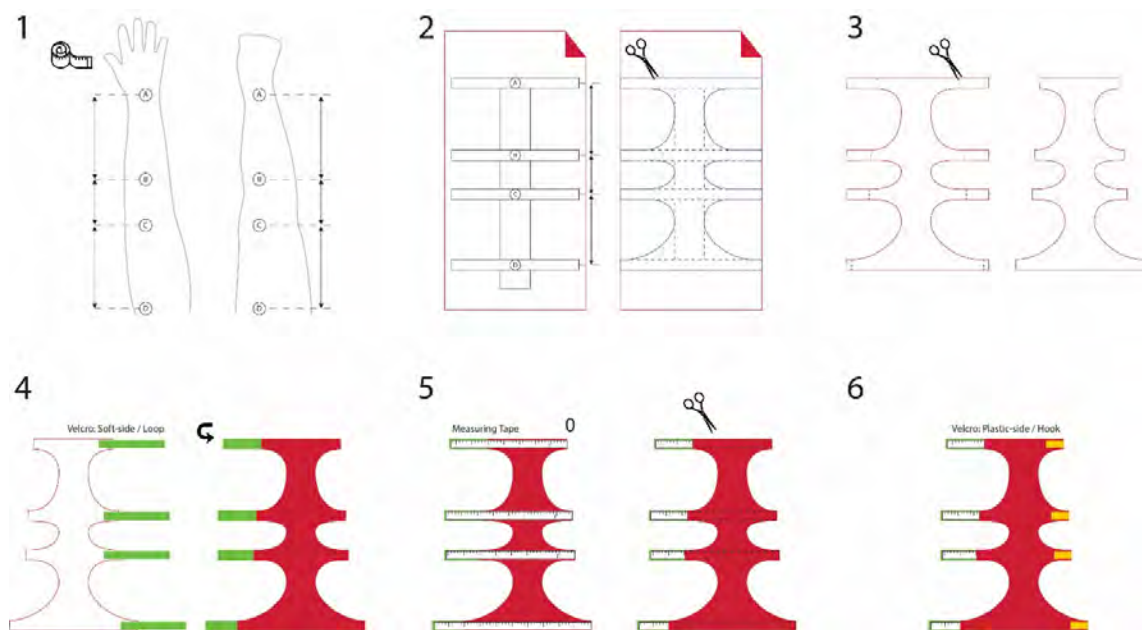


Figure 6-10 Instructions for making Wrap-to-Measure

Various types of fabric and hook-and-loop fasteners (velcros) were provided to the participants. They selected the materials they wanted to use, took measurements, decided on the sections they wanted to monitor and cut the fabric to make one Wrap-to-Measure that was tailored for their affected limb (Figure 6-11). Participants worked together and with the workshop facilitators during this making activity. During the workshop, possible ways to tailor the Wrap-to-Measure for the particular needs of the participants were discussed.



Figure 6-11 Participants making Wrap-to-Measure during the workshop

Personalisation:

It's an evolving condition and you need to evolve with it. LAURA

Personalisation means approaches to tailor the support provided for the specific needs of the individuals. The design of the cultural probe was guided by the interviews conducted by the participants and considering the needs of the individuals. The participants had built their personalised self-management routines and approaches. The cultural probe was designed to accommodate such different approaches to self-management. Moreover, probes were included to facilitate and encourage the participants to personalise their cultural probe. Participants were encouraged to modify the diary and add or remove pages as they wished. The pages were loose to allow participants to compare the changes in their swelling by having the self-documentation pages side-by-side. Having a loose structure instead of a booklet also emphasised that there was not a predefined order for filling the

diary. Blank pages were included. Possible triggers, alternative self-management and self-monitoring strategies were provided in the form of stickers. As shown in the Appendix F1, extra stickers with emoticons and blank stickers were also included.

Peer support:

You meet some people that inspire you. Sometimes you see someone and you think I can do that too. HELEN

A peer support approach was implemented by providing probes to encourage 1) 'thinking and reflecting' at a peer support meeting [After the support group meeting... I told... I felt...], 2) reading about what other PLWL experienced and suggested (all pages of My-Lymphy-Diary included a relevant quote about the page) (Figure 6-12).

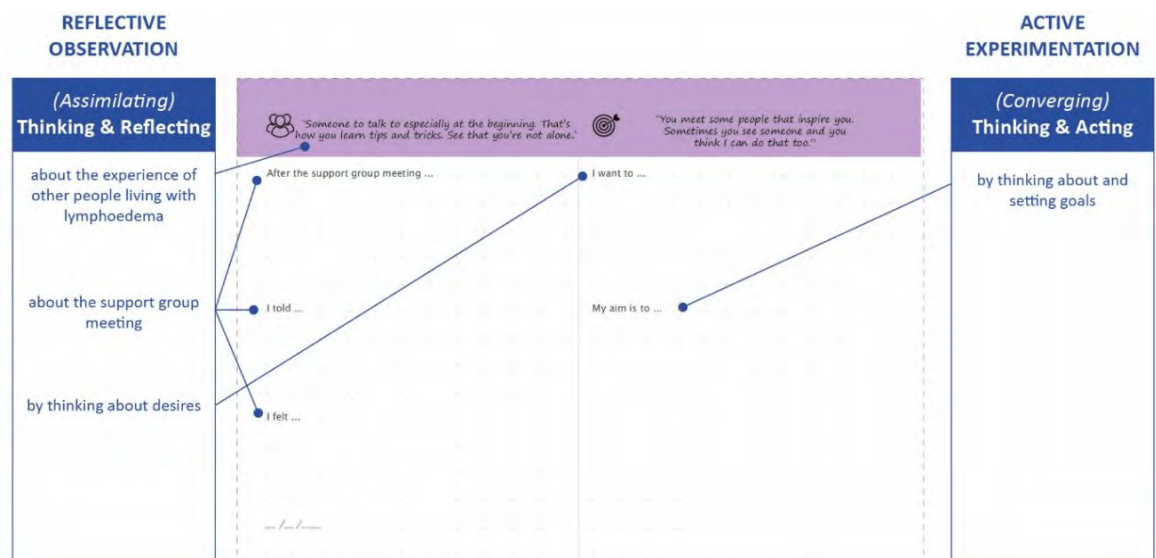


Figure 6-12 Peer support approach of My-Lymphy-Diary explained

Collaborative Professional Support:

I would like to know that all eventualities are talked through. We [me and my therapist] would try and understand and talk about why things don't work for me...
LESLEY

A collaborative support approach was implemented, by providing probes to encourage `thinking and reflecting` after the meeting with the lymphoedema therapist [After seeing my therapist... I told... I felt...] (Figure 6-13).

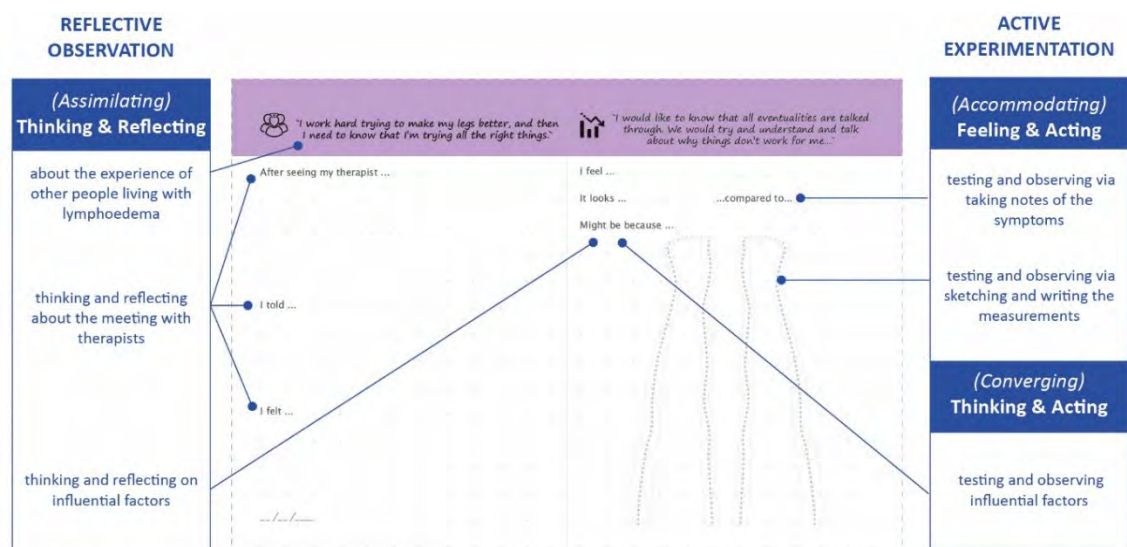


Figure 6-13 Collaborative professional support approach of My-Lymphy-Diary explained

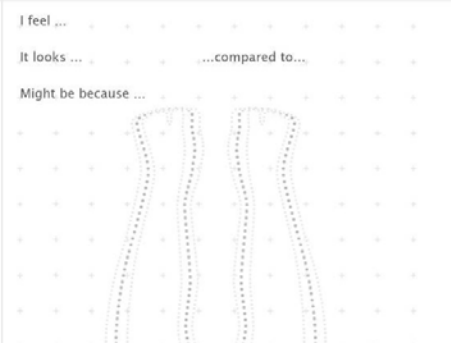
6.1.3 Summary

This section described the design of the cultural probe. The cultural probe was composed of My-Lymphy-Diary (a reflective self-management journal) and Wrap-to-Measure (a self-monitoring tool). Wrap-to-Measure was tailored and made by the participants during a workshop. It was designed to support participants' self-monitoring and complement the My-Lymphy-Diary. My-Lymphy-Diary was composed of 14 pages with various probes that implemented design strategies to support self-management. The cultural probe intended to support empowerment by facilitating participants to `think,

reflect, feel and act` on their self-management and followed the support needs of PLWL at the `Experimental Stage` of the empowerment journey. The cultural probe was introduced to PLWL during the co-making workshop. Participants used/filled the cultural probe and mailed their My-Lympho-Diaries back to the researcher within a period of two months. The structure of the cultural probe is summarised in Table 6-1.

Table 6-1 Summary of the design strategies implemented in the cultural probe

	Design Strategies to Support Self-Management - Experimental Stage	Related Experiential Learning Style	Page Structure and Included Pre-defined Captions
COMPETENCE	Skill-development: Experiential learning: testing, observing and reflecting on a variety of management strategies.	Diverging Feeling-Reflecting	I feel better when... [sticker of an alternative management strategy] (might) make my lymphoedema better because... [sticker of an alternative management strategy] (might) not affect my lymphoedema because...
	Self-monitoring: Self-monitoring (objective or subjective) to understanding the influence of the alternative management strategies and possible triggers.	Diverging Feeling-Reflecting	I don't feel well when... [sticker of a possible trigger] (might) trigger my lymphoedema because... [sticker of a possible trigger] (might) not affect my lymphoedema because...
	Personalisation: Gradually add new and alternative management strategies and, explore possible triggers.	Converging Thinking-Acting	Stickers: Facilitate the exploration and documentation of alternative management strategies, possible triggers and self-monitoring strategies as described by other PLWL. Wrap-to-Measure: facilitating self-monitoring of the circumferential changes to allow observing the influence of various self-management strategies and possible triggers

		Accommodating Feeling-Acting	
		Diverging Feeling-Reflecting	<p>I do/don't monitor my swelling because...</p> <p>[sticker of an alternative self-monitoring strategy] I prefer because...</p> <p>[sticker of an alternative self-monitoring strategy] I don't like because...</p>
AUTONOMY	Goal-Setting: Setting goals for habit building. Gradually integrate self-management to everyday life.	Converging Thinking-Acting	<p>I want to...</p> <p>My aim is to...</p>
HABIT	Goal-Setting: Setting goals for habit building. Gradually integrate self-management to everyday life.	Converging Thinking-Acting	<p>My plan is...</p> <p>[a blank table]</p>
PSYCHOLOGICAL	Peer support: to get motivated by seeing positive examples. For learning tips and tricks (alternative strategies and possible triggers)	Assimilating Thinking-Reflecting	<p>Quotes at the banner of each page. For instance: "sometimes you feel like you are doing something endlessly and not seeing the results fast. Lymphoedema comes down to time. It's not a fast thing to change"</p>
IDENTITY	Goal-Setting: Setting goals for habit building. Gradually integrate self-management to everyday life.	Diverging Feeling-Reflecting	<p>I do/don't monitor my swelling because...</p> <p>[sticker of an alternative self-monitoring strategy] I prefer because...</p> <p>[sticker of an alternative self-monitoring strategy] I don't like because...</p>

	Personalisation: Gradually add new and alternative management strategies and, explore possible triggers.	Assimilating Thinking-Reflecting	My magic compression garment would... I wish, I had...
SUPPORT	Collaborative Professional Support: Collaborative for exploration of possible triggers and alternative strategies.	Assimilating Thinking-Reflecting	After seeing my therapist... After the support group meeting... I told... I felt...

6.2 Results of the Workshop and Cultural Probe with PLWL

In this section the results of the workshop and the cultural probe study is presented.

The results of the cultural probe study were twofold: 1) The responses of the participants to the probes provided insights about how they perceived and reflected on the strategies to self-management support; 2) The ways participants actually used the cultural probe presented insights about how they interacted with these probes.

6.2.1 Skill-Development

Participants described their self-management strategies and the influence of certain triggers in their diaries, with the use of provided stickers and probes (for example see Figure 6-14). All the study participants reported that they were wearing their compression garments as a part of their self-management routine and perceived it beneficial following subjective or objectives ways of self-monitoring. Elizabeth noted how she explored the compression strategies that worked for her: *“Over time I have learnt when to wear additional compression”*. They also wrote about add-on strategies to complement wearing compression garments. Jennifer described how she explored the effects of certain

strategies: “[elevation] [might not affect my lymphoedema because] but if I keep my legs elevated (which I did) the measurements weren’t too different from my norm”. Margaret expressed the ways she monitored her lymphoedema and how she adapted her self-management accordingly:

I can tell if it gets worse with certain garments I wear. I do more exercises on my arm if I feel the swelling has increased... If I have been overdoing things and become tired, I have found that my arm becomes heavy and begins to ache.
MARGARET

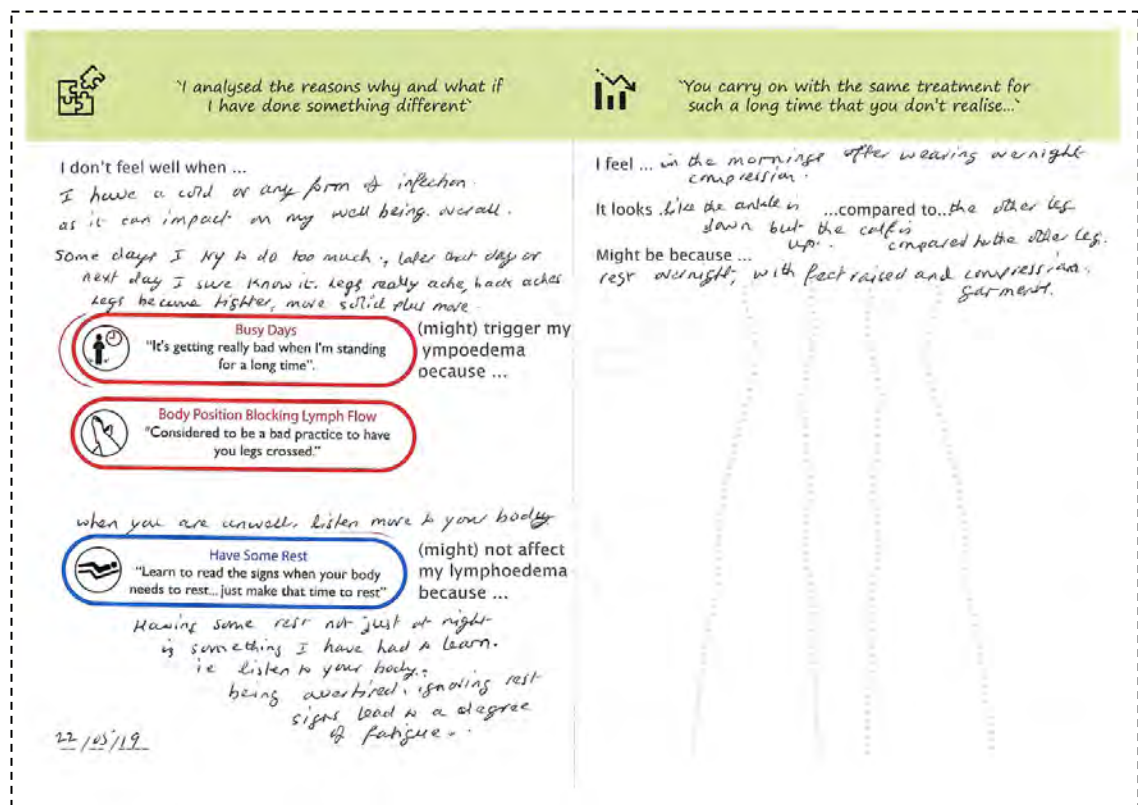


Figure 6-14 Skill-development page from Elizabeth's My-Lympho-Diary

Participants described their experiments in finding better ways that suited their particular needs, these management strategies could be complex:

I have a clear indication if I'm doing the right things or need to try something different. Sometimes I wear double layer of compression garments and other times I wear one layer with a farrow wrap. Sometimes the double layer can become painful especially around toes/foot. I then take off one layer- either a stocking or my toecaps/I sometimes replace the toecaps with a bandage, I bandage each toe individually. This is more comfortable especially when I'm in bed. I usually only wear leg garments to bed with toecap or bandage. When the tissue at the top of my

leg was becoming firmer... I tried putting a thigh length stocking on under my one-legged panty hose instead of on top of it and it worked. Within a couple of days, the tissue had become softer because the compression was tighter directly over that area. MARY

While reporting on the influence of management strategies and possible triggers to their lymphoedema, participants also articulated their understanding of the reasons behind these effects:

...because the fluid/protein within the areas of lymphoedema will move from different parts of the limb so on occasions the calf maybe larger and the ankle/thigh slightly lower, this can be due to the areas which are blocked or damaged and unable to drain via lymph channels and nodes. ELIZABETH

Developing self-management skills was perceived as beneficiary also for participants' psychology. Elizabeth described the change she made in her self-management as a way to feel better even if it did not directly affect her swelling "*there is not a way to measure it physically. However mentally it will make me feel better*". Mary wrote "*I always feel recharged/inspired when I learn something new to try*".

Use of the Cultural Probe for Skill-Development: "It didn't really change my self-Management... but it made me think more about it"

All the participants utilised the skill-development pages of their diaries, and expressed that the cultural probe made them more aware of their self-management:

It was something that made me stop and think about what I do, how I do it, could I change it, do I need to change, how could I adopt and accept any new treatments and information make changes that I need to? Make me think of my garments, how easy or hard to put on, pull off. It made me think about what's important to me and what is not as important to me. ELIZABETH

Jennifer described that even though the diary made her think more about her lymphoedema, the diary "*didn't really change my self-management. I have lived with the swollen leg for 33 years now, but I do not have severe lymphoedema*". Jennifer noted that she did not find the 'skill-development' pages useful for her self-management since she was only wearing compression garments, but did not have add-on strategies. Elizabeth

suggested emphasising the cornerstones of self-management among the listed self-management strategies. Mary wrote that My-Lymphy-Diary “*could be a very useful tool to compare measurements with exercise and treatment plans*”. Jennifer found the diary useful at focusing the effects of specific events on her lymphoedema such as holidays and occasions when she was not feeling well. Yet, she found it time consuming for everyday life and hence not something she would like to use every day.

6.2.2 Goal-Setting

The self-management goals set by the participants included persistence in doing self-management, keeping their limbs ‘as small as possible’ and decreasing the impact of their swelling on their daily life (Table 6.2). Participants recognised that lymphoedema could not be totally controlled, yet they perceived self-management as a way to feel in control. Mary explained: “*You realise, the more work you put into managing the condition the better you have the chance of keeping it under control*”. Elizabeth described: “*I do not allow my lymphoedema to control me as a person, mentally and physically. I control my lymphoedema and thus will spend whatever, however needed*”. She described an integrated motivation and noted that maintaining her swelling was important for her. Participants explained the influence of lymphoedema on their everyday life. One of the reasons to persevere with self-management was to minimise such effects of lymphoedema. Sarah wrote that her aim was to “*maintain any reduction so that [her] feet feel comfortable and an evening out is more enjoyable. An evening at the theatre can be spoilt if the swelling becomes painful*”.

The ‘desires’ of participants were not always in-line with their ‘aims’. For instance, Jennifer wrote about her dilemma. She wrote that she wanted to take her stockings off. Yet,

she was aiming to keep her compression garments on: “[My aim is to] keep the stocking on even if the leg does feel hot & uncomfortable!” (Figure 6-15).

I don't always succeed, but it [goal setting] makes me do more... it makes me to think about it.

Ohh that's gone down a bit, that's good! That gives you a bit of incentive to keep at it, and I'll start doing the lymph drainage then.

I want to ...

Take my stocking off!

My aim is to ...

Keep the stocking on even if the leg does feel hot & uncomfortable!

I feel ... fed up

It looks ... that looks a bit bigger

...compared to... leg

The heat!

Figure 6-15 A Goal-Setting page from Jennifer's My-Lymphy-Diary

Margaret had a LVA (Lymphatic Venous Anastamosis) surgery while she was completing her diary. She described her expectations from the LVA surgery as “*hopefully being able not to wear my garment again!*”. Even though participants knew that lymphoedema was a chronic condition which required them to wear compression garments on a daily basis, they still noted their hopes and desires for taking off their garments.

Elizabeth explained:

[I wish I had] a magic wand and did not have to live and manage my lymphoedema on daily basis. It would be lovely if there was a way to resolve having lymphoedema at all. So I guess I will settle for having an excellent garment... ELIZABETH

Table 6-2 Participants' Self-Management Goals

Persistence in self-management	<p>Jennifer: "keep going"</p> <p>Sarah: "not give up on trying different things"</p> <p>Elizabeth: "stay up to date on developments"</p> <p>Mary: "You realise the more work you put into managing the condition the better chance of keeping it under control"</p> <p>Jennifer: "[I want to] take my stocking off. [My aim is to] keep the stocking on even if the leg does feel hot & uncomfortable!"</p>
Keeping it as small as possible	<p>Elizabeth: "keep [her] affected lower limb down to a manageable level where by it looks a similar size to the unaffected lower limb"</p> <p>Mary: "as small as possible"</p>
Decreasing the impact of their swelling on their daily life	<p>Sarah: "maintain any reduction so that [her] feet feel comfortable and an evening out is more enjoyable. An evening at the theatre can be spoilt if the swelling becomes painful".</p>
Feeling as if in control	<p>Elizabeth: "I do not allow my lymphoedema to control me as a person, mentally and physically. I control my lymphoedema and thus will spend whatever, however needed"</p> <p>Jennifer: "to feel as if [she is] in control"</p>
Integrated to everyday	<p>Sarah: "a life to live and families to look after", she aimed to "to be as flexible as possible. Sometimes family commitments take priority. Keep to a routine whenever you can.".</p> <p>Elizabeth: "I still live and do what I want to do with my life". "have aspects as part of the each day not as additional parts unless in certain circumstances".</p> <p>MARY: "I find if I take time out to rest i.e.. when I'm watching tv or reading etc. with my leg elevated I'm then able to carry on later on in the day/evening and do the things I had planned to do"</p>

Participants expressed the importance of being flexible with their management to be able to balance that with other priorities in life. Sarah noted that, she and the other participants had *"a life to live and families to look after"*, so she aimed to *"to be as flexible as possible. Sometimes family commitments take priority. Keep to a routine whenever you*

can". It was important for Elizabeth to have self-management "*as part of each day, not as additional parts unless in certain circumstances*". Mary noted her strategies in integrating her self-management into daily life:

I find if I take time out to rest i.e.. when I'm watching tv or reading etc. with my leg elevated I'm then able to carry on later on in the day/evening and do the things I had planned to do. MARY

Use of the Cultural Probe for Setting Goals: "Look ahead in a more positive manner"

All the participants wrote their aims and desires in their diary. Elizabeth suggested facilitation of setting such goals and aims with lymphoedema therapists. Jennifer wrote that writing her goals made her "*look ahead in a more positive manner*".

In the diary, participants described their self-management routines as regular yet flexible, and integrated to their everyday life. Two of the participants wrote their daily routines (weekly exercise plans, everyday morning and evening routines of self-management) in the diary, while one wrote her everyday strategies in general. Jennifer noted that preparing a self-management programme was helping her by "*planning ahead*". Sarah wrote that she perceived having a regular routine essential: "*[my plan is] to keep to a regular and manageable routine. If something comes up then you can generally cope with it*". Elizabeth described the routine she developed over the years:

I get up each day and take a look, a good look at both legs and think yes today I can do 5-10 mins SLD, 5-10 mins exercise and massage the calf area further. Today I can do, spend up to 20 mins morning and evening then do all that planned that day. ELIZABETH

After describing her routine Elizabeth emphasised that: "*I still live and do what I want to do with my life*".

6.2.3 Self-Monitoring

Four of the participants noted that they measured their affected limb occasionally. They found it easy to take pinpoint measurements and compared it with their previous measures. Three of the participants said they took copies of their clinical measurements. Sensations, appearance, texture and fit-of-clothes were common ways of subjective self-monitoring among the participants. Mary wrote *“you always know when the swelling is worse because you feel more uncomfortable and the limb feels heavier. You can also see a difference in a mirror. Shoes and clothes also feel tighter”*. The methods used by participants to self-monitor their lymphoedema are listed in Appendix F2. Elizabeth explained how her self-monitoring approach changed whilst gaining expertise: *“I’m experienced in doing the limb measurements, which over the years I have kept a diary record. I don’t record measurements as frequently anymore, as I can now do a very good visual measurement”*.

Four main reasons for self-monitoring were described by the participants: 1) to explore if management strategies were effective, 2) to adapt their self-management accordingly, 3) to know when professional help was needed, and 4) to sustain motivation. Reasons for self-monitoring as described by the study participants are provided in Appendix F3.

Participants noted that having a reduction in their swelling made them feel better, yet fluctuations were challenging for them. Sarah explained that staying positive even if *“nothing seems to work”* was expressed as being important by therapists, yet it was difficult. Angela noted that her leg looked *“awful”* to her eyes and she felt *“sad and upset”* when her leg swelled. Jennifer used a sticker to note how the permanence of the condition made her feel (Figure 6-16).

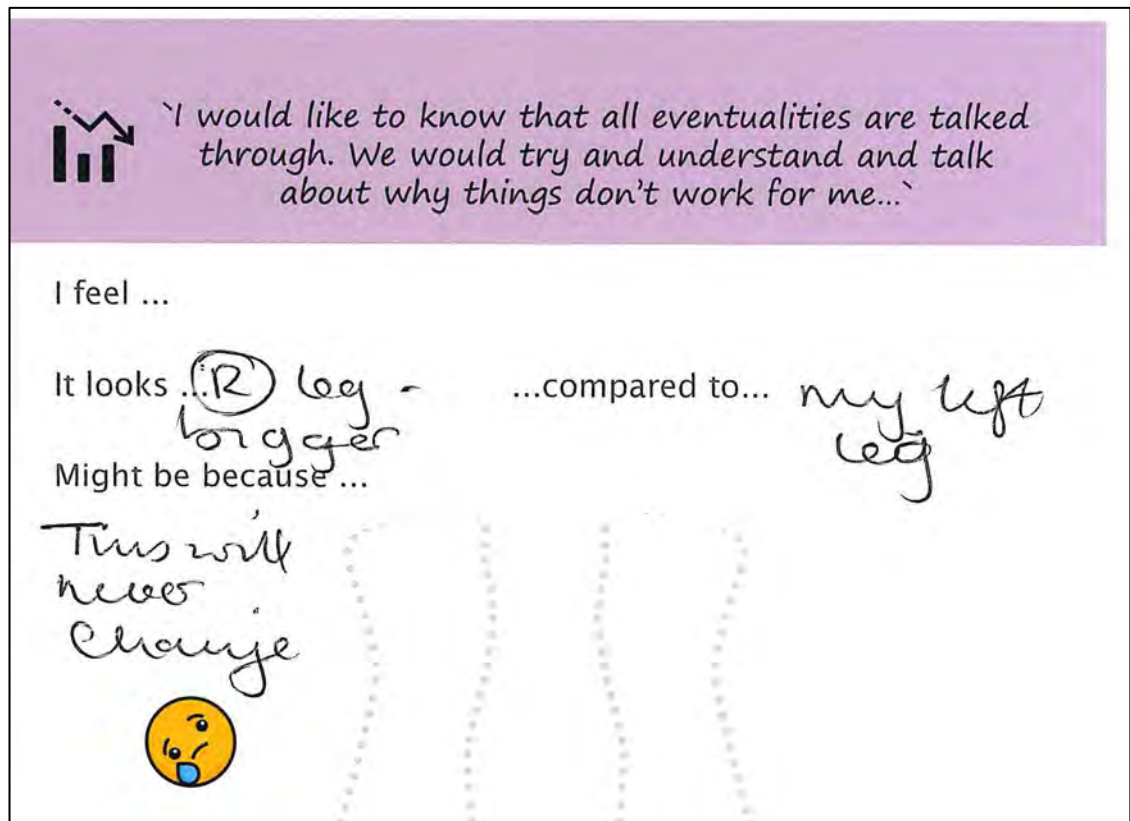


Figure 6-16 A self-monitoring page from Jennifer's My-Lymphy-Diary "This will never change"

Use of the Cultural Probe for Self-Monitoring: Wrap-to-Measure "Is an excellent idea... but I did not use it"

The cultural probes (My-Lymphy-Diary and Wrap-to-Measure) were introduced to the participants during the workshop. The initial response of the group to making a Wrap-to-Measure for themselves was positive. Some expressed that they liked the idea of being able to measure themselves. Elizabeth said that the Wrap-to-Measure was a brilliant idea, which should be patented. Lesley said that *"That would be so good, to just monitor it yourself"*. She emphasised the benefits of Wrap-to-Measure compared to a tape measurement as having a set distance between the sections:

If you think of a leg and you put a tape round it, they put a mark on it. You can do it lots of different ways and its never the same measurement twice, that [wrap-to-measure] makes it accurate. They sometimes change it, it is not consistent. LESLEY

During the co-making workshop, six of the participants created their own Wrap-to-Measures tailored for their limbs. Two of the participants, Sarah and Elizabeth, did not

made a Wrap-to-Measure. Sarah explained that she did not need one because she did not measure frequently. She said that when she measured, she was doing that only for her feet. In her My-Lymph-Diary, she wrote that she wished she had made a Wrap-to-Measure during the workshop and thought that it was better than a tape measure. She noted that taking measurements at clinics with a Wrap-to-Measure would be easier. Elizabeth was the other participant who did not make a Wrap-to-Measure during the workshop. She said that she was already experienced in taking measurements with tape measures and was not measuring as frequently as she used to do. She expressed that she used to keep a written record of her measurements, and now after her surgery she preferred doing a visual monitoring instead. She perceived Wrap-to-Measure as useful for new patients. She suggested adapting that into clinics and offering patients the Wrap-to-Measure with a booklet to keep records.

Even though the group said they perceived Wrap-to-Measure useful, most of them did not use it during the two months period of the cultural probe study. Participants' usage behaviour of the cultural probe and related comments are provided in Appendix F4. One of the participants who wrote down circumferential measurements in her diary was Jennifer (Figure 6-17).

While making her Wrap-to-Measure during the workshop, Margaret expressed that she was excited to try it. She said that she could not use a tape measure herself for her arm. Margaret was the only study participant with lymphoedema in her arm among the group. She added that it was possible for one to measure their legs by themselves, but arms were more difficult. After using the Wrap-to-Measure she wrote in her diary that she preferred to have her arms measured at the clinic instead. She noted that she found using Wrap-to-Measure by herself difficult. Mary made a Wrap-to-Measure and wrote *"I thought it's a really good idea. It's quick and easy to use and ensures the measurements are always*

taken from the same point on the leg/arm". She said "the only problem was the double-sided Velcro became detached after use. It would be better if it was stitched on". However, she did not write the measurements of her leg in the diary. Angela made a Wrap-to-Measure during the workshop. In her diary, she wrote that Wrap-to-Measure was not accurate and she "found it very fiddly" saying that she preferred tape measures instead.

Top Quotes:

- "You build up confidence by very small steps. You tackle one small issue at a time."
- "It goes up and down. Even if it goes up you have to be still positive. Accepting that it can go up. Especially if it's particularly warm day or being on it too long."

Left Column (I don't feel well when ...):

When I have had a period of inactivity. Have had a viral cough, & have felt tired, so was less active.

- inactivity (might) trigger my lymphoedema because ...

not using my legs enough, venous return, & venous return.

But if I keep my legs elevated (which I did) - the measurements weren't too different from my norm. (might) not affect my lymphoedema because ...

13/5/19

Right Column (I feel ... that possibly my measurements have increased ...):

It looks ... compared to ...

Ⓡ leg looks bigger Ⓛ leg

Might be because ...

no comparison on this leg for 3 days

Measurements (circled): 32, 49, 46, 60, 28, 51, 50, 62

Figure 6-17 Self-monitoring page from Jennifer's My-Lymphy-Diary: Example of Self-Monitoring via Writing the Measurements

In the cultural probe, self-monitoring could also be done by taking notes of the symptoms and sketching the affected limb. Three participants (Elizabeth, Jennifer and Angela) took notes about their symptoms on their diaries. Only Mary sketched about her

lymphoedema on her diary (Figure 6-18).

Top Left: You always set up with the compression and then you find the things to add-on...

Top Right: I was so convinced that my leg was getting bigger... They measured and said "no, it is actually smaller" but it's got bigger in different areas

Left Column:

- I feel better when ... I do some moderate exercise i.e. walking, swimming, stretching and then rest with my leg elevated
- I always use the upstairs toilet in the day it makes me walk up and down stairs more often.
- Exercise acts like a pump to move the fluid more quickly and clear it from my body.
- SLD** Simple Lymphatic Drainage "Encourages lymph to drain out. It's important that you're taught by a specialist."
- Drink plenty of water after wards.
- (might) make my lymphoedema better because ...
- (might) not affect my lymphoedema because ...
- Fit of Clothes & Shoes** "some days you wake up and put your shoes on and some days... you find another pair."
- Some days you trousers are too tight - wear wide leg linen ones they're cool & comfy!
- I use a long handled shoe horn to get my shoes on.
- 13/05/19

Right Column:

- I feel ...
- It looks ...
- ...compared to...
- Might be because ...
- ankle
- mid-lower
- upper edge of knee cap
- mid thigh

Figure 6-18 Self-monitoring page from Mary's My-Lymphy-Diary: Self-Monitoring via Sketching

Sarah, Margaret and Mary did not write down their symptoms or how they felt. They used their diaries to explain their self-management strategies and possible triggers in a reflective manner. Margaret described *"initially I found this diary somewhat overwhelming and really did not know where to start"*. Sarah suggested adding a guidance sheet and noted that *"some of the printed comments don't always help with what you are trying to describe and explain"*. Jennifer wrote that *"I feel..."* section was not necessary but would be good to keep *"It looks... compared to... Might be because..."*

6.2.4 Personalisation

The self-management strategies participants explained and chose from the provided stickers showed a great variety. The two cornerstones of self-management that all the

participants agreed on the benefits of were compression and skin care, but there was no consensus about the effectiveness of other strategies. Participants emphasised that, even if a self-management strategy was effective for many, it could still be ineffective for some others. Hence, they underlined the importance of exploring the strategies that were beneficial for the individual. They shared their experiences of unexpected results from certain self-management strategies. For example, Lesley said *“We are all slightly different, exercise is meant to be good and it is for many. But, if I go for a walk, you won't believe what happens to my legs”*. Sarah explained that Manual Lymph Drainage (MLD) worked well for her, while she could not *“get the same results”* from Simple Lymph Drainage (SLD). Yet, participants had different opinions about the effectiveness of some of the strategies. Angela wrote that the increase in her swelling might be because of not being as thorough with her SLD. Another aspect of personalisation was the duration of the self-management. Sarah advised incremental increase that matches the individuals' needs: *“take exercise gently at first and build your routine at a pace that suits you”*.

Personalisation of the Cultural Probe by the Participants:

Participants were encouraged to change their diary as they wished, and to make it more useful for themselves during the workshop. Participants altered and personalised their diaries to varying extends. The pages of My-Lymphy-Diary were loose and did not have page numbers. Yet, most of the participants returned their diary pages in the provided order. Sarah numbered the pages. Only Margaret and Jennifer shuffled some of the pages of their diaries. Sarah noted that *“a guidance sheet might be helpful”* and she did not change her diary apart from crossing over some of the pre-defined captions. Jennifer used the stickers and wrote her own captions for explaining her management strategies and possible triggers. Even though, she filled most of the “I feel...” captions in her diary, she

noted that it could be erased. Some participants crossed the pre-defined captions to write their strategies in different ways (for example Figure 6-19). Sarah wrote *“some of the printed comments don’t always help with what you are trying to describe and explain”*. Especially the pre-defined caption of “Might not affect my lymphoedema because...” was rarely used and crossed in most pages. Instead, the participants used that space to note other influential factors.

Even though participants were requested to send their diaries back within two months’ time, no specific timeline for filling the diary was defined. Elizabeth filled her diary in one day as she noted the same date on all pages. Jennifer wrote down intermittently. Mary noted the date on the first page only. The other participants did not fill the date sections at all, so it was not known how frequently they wrote to their diaries.

The image shows a handwritten page from Sarah's 'My-Lympho-Diary'. The page is divided into several sections with pre-defined captions, some of which have been crossed out or modified.

- Top Left:** A yellow header with a puzzle piece icon and the text: "It's a matter of trial and error... keep trying different things."
- Top Right:** A yellow header with a target icon and the text: "Goals to keep you motivated on tasks and to remind you that this is going to take time... otherwise you can get very despondent with the treatment quickly... You need to give it time"
- Left Column:**
 - Handwritten text: "I feel better when ... I am able to self-manage my condition and get on with my life"
 - A blue-bordered box with a wavy line icon, containing the text: "Elevate while Sleeping 'I do put a cushion under my legs while sleeping'"
 - Handwritten text next to the box: "(might) make my lymphoedema better because ... it helps drainage"
 - A blue-bordered box with a person icon, containing the text: "Activity 'We need to keep active. Muscle pump is the only pump the lymphatic system has'"
 - Handwritten text next to the box: "(might) not affect my lymphoedema because ..."
 - Handwritten text at the bottom: "Take exercise gently at first and build your routine at a pace that suits you."
- Right Column:**
 - Handwritten text: "I want to ... If you are not sensible about self-management then life will become more difficult."
 - Handwritten text: "My aim is to ..."

Figure 6-19 A Goal-Setting page from Sarah's My-Lympho-Diary

Empty stickers had been included to the diary to encourage participants to add their own strategies. Some participants preferred writing down their strategies and triggers instead of using the stickers. Still, all the participants used some stickers. Mary wrote “*I liked the stickers I could relate to a lot of the comments on them*”. Pre-defined sticker spaces had colour codes to match the sticker functions with the pre-defined captions. Stickers of alternative self-management strategies were blue, possible triggers were red and alternative self-monitoring strategies were grey. Yet, participants used these stickers in a mixed manner to explain their strategies. Stickers were also used out of the pre-defined spaces and on extra pages added by the participants (Appendix F1). Extra blank pages were included with the My-Lymphy-Diary. Participants were encouraged to skip or add pages as they wished. Three of the participants added an extra page, two of these were paragraph style reflective writing about participants’ diagnosis and self-management experience. Elizabeth used her remaining stickers to further explain her self-management strategies and categorised them into two: 1) daily, and 2) while travelling and hot weather (Figure 6-20).

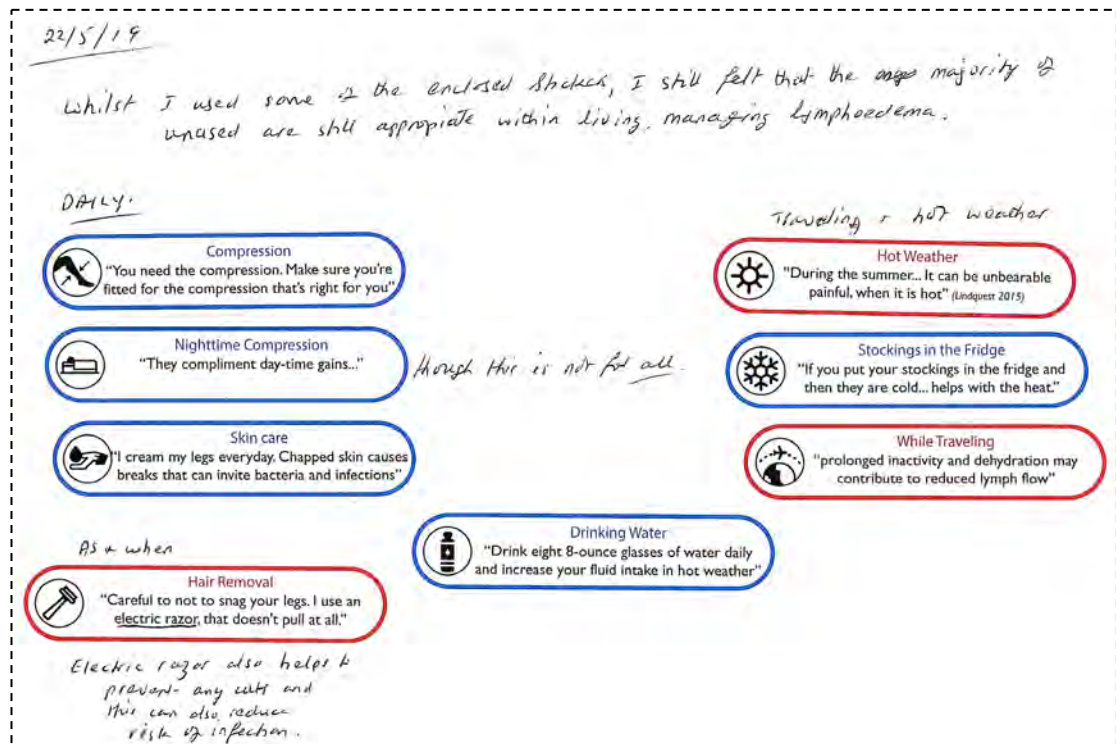


Figure 6-20 An extra page added by Elizabeth to her My-Lympho-Diary

6.2.5 Peer Support

All being part of a peer support group, participants wrote that peer support helped them psychologically, encouraged them for managing their lymphoedema, and taught and inspired them for trying new strategies. Recognising that there were other people with lymphoedema was important for participants. Mary wrote that *"you feel better when you realise you're not the only one with this condition especially when it's first diagnosed"*. Another advantage of support groups was learning from people who were going to through a similar experience. Elizabeth noted *"the support group can give some tips that therapist may not know"*. Learning tips was encouraging them to keep working at their lymphoedema. Mary wrote that after the support group meeting, *"I always feel recharged/inspired when I learn something new to try"*. Jennifer said that she felt *"supported and energised"* after the support group meeting, but she also felt *"more*

confident to contact the clinic". Sarah noted that it *"can be really difficult learning to live with this condition"*. Participants explained their strategies to cope with having a chronic condition. Elizabeth explained that *"to adjust to having a lifelong chronic condition"* she wanted to keep her *"mind healthy and alert"*. They explained the benefits of support groups: Mary said *"you feel better"* when you meet others with lymphoedema and Elizabeth noted *"we support each other by staying positive"*. Sarah and Elizabeth took notes on the quotes from PLWL in their My-Lymphy-Diaries. They explained their opinions about these quotes and marked them. Jennifer noted that the diary made her think more about *"how much group support helps"*.

6.2.6 Collaborative Professional Support

Participants explained the importance of the support they got from their lymphoedema therapists. They explained how grateful they were for the provided services. Mary wrote, *"the clinic do an excellent job with limited staff and available time and are always willing to help and offer advice"*. Mary explained how her appointment with her lymphoedema therapist motivated her *"I'm encouraged to keep working hard"*. Participants primarily wanted to talk about their specific problems and hear advice from their lymphoedema therapists. Even though some mentioned that there was not always enough time for discussions during routine clinic appointments, others explained how they were able to improve their management thanks to their lymphoedema therapists. Jennifer explained that she felt happy that she was *"listened to and action had been taken"*. Elizabeth highlighted that she was also listening to them to work collaboratively with her therapist: *"my therapist listened to me and I too them. We work together for a plan to go forward with my self-management and maintenance of the lymphatic limb"*. Jennifer wrote

her desire to contact the clinic to discuss the problems with her compression garments. She described her proactive approach and noted that she wanted “*to feel as if [she is] in control*”. Skin care, one of the cornerstones of self-management, was perceived fundamental and easy compared to others. Sarah wrote in her diary “*my practitioner always notices my skin is in a good condition. I find moisturising my leg is the easiest part of self-management*”. Some participants raised questions about the unknowns to lymphoedema even by the professionals. Elizabeth wrote, “*[I feel] sometimes all my questions cannot be answered as no one has all the knowledge and skills and information*”. Jennifer explained the effects of the hot weather during her holiday and raised a question: “*Does the stocking do more damage than good when the weather is very hot?*”

6.2.7 Summary

This section presented the results of the cultural probe study and co-making workshop. Participants’ experience with the cultural probe provided insights about the design strategies to support self-management (Table 6-3).

Table 6-3 Summary of the results of the Cultural Probe and Co-Making Workshop

	Components of Self-Management Journey	Results of the Cultural Probe and Co-Making Workshop with PLWL
SKILL-DEVELOPMENT	Competence Autonomy	<p>Encourage reflective observations and active experimentations on influential factors.</p> <p>Encourage learning new management strategies and inform about possible triggers.</p>
GOAL-SETTING	Autonomy Habit Identity	<p>Encourage setting self-management goals. Explain that seeing the results in lymphoedema will take time. Facilitate setting feasible goals.</p> <p>Accommodate different types of goals. Emphasise the importance of integrating self-management to daily life in a balanced way. Provide encouragement for the maintenance of self-management, without inducing obsession.</p> <p>Encourage building routines.</p>
SELF-MONITORING	Competence Autonomy	<p>Accommodate both objective and subjective symptom tracking, and highlight their relations when possible (for example: is pain correlated to increase in circumferential measurements)</p> <p>Accommodate self-monitoring to understand 1) effectiveness of self-management strategies, 2) how to adapt these strategies when needed, 3) influence of possible triggers to lymphoedema, and 4) when professional help is needed.</p> <p>When swelling monitored to be increasing, 1) provide psychological support and guidance, 2) explain viable expectations and that self-management strategies can take time to show any benefits, 3) explain the possible effects of common triggers like weather and tiring the limb.</p>
PERSONALISATION	Competence Autonomy Identity	<p>Facilitate tailoring self-management plans according to individual needs and for particular influential factors.</p> <p>Support personalisation of the provided tools and keep the user in control.</p> <p>Allow and encourage different self-management plans for out-of-routine occasions, such as when travelling.</p>
PEER-SUPPORT	Competence Autonomy Psychology Identity Support Network	<p>Encourage sharing success stories among PLWL.</p> <p>Facilitate sharing suggestions and tips about self-management among peers.</p>

COLLABORATIVE PROFESSIONAL SUPPORT	Competence Autonomy Habit Psychology Support Network	Facilitate collaboration with healthcare professionals while exploring effective management strategies and possible triggers . Encourage collaboration with healthcare professionals while setting self-management goals and plans
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Participants had different approaches to filling their My-Lympho-Diaries. The `reflective observations` sections in the diary were used more frequently than the `active experimentations` sections. All the participants reflected on their self-management strategies and routines. However, only three participants wrote about their daily observations and engaged in active experimentation side of the diary.

6.3 Design of the `Persona Journeys`

In this section, the development of the `persona journeys` is presented. Persona journeys are developed as design probes for the group interview study with lymphoedema therapists. The results of the studies with PLWL presented in this thesis have demonstrated that PLWL were going through a journey and their needs were changing by increased empowerment. Hence, it was important to convey this journey and its stages (novice, experimental, empowered) as experienced by PLWL. It should be noted that, every lymphoedema journey is unique to the individuals, and `persona journeys` do not intend to generalise or categorise these diverse experiences. Instead, the aims of the persona journeys are: 1) to sensitise the participants of this study (the lymphoedema therapists) about the insights gained from PLWL in an anonymous way and through describing repeated themes, and 2) to facilitate conversations about PLWL's changing needs during the group interview.

The results showed some fundamental differences about the start of lymphoedema journeys of people living with primary and secondary lymphoedema. Hence, two personas, one with primary (Daisy) and the other with secondary lymphoedema (Abby), were developed. People living with primary lymphoedema had usually been experiencing symptoms and trying to find the reason of their swelling for very long periods. Hence, for many people with primary lymphoedema, diagnosis was a relief to finally being offered ways to manage this condition. However, lymphoedema diagnosis after cancer treatment was usually sudden, and for many people it was perceived as an untold side effect, a reminder of cancer and a source of frustration. Hence, `novice stage` of the personas were different and specific to the primary or secondary lymphoedema experiences. Research showed that they shared similar experiences at the experimental and empowered stages, and hence these stages were common. The persona that had been created for the interview study with PLWL, Abby, (see section 5.2.2.3) had secondary lymphoedema and this was kept consistent with that version (Figure 5-3). The stages these personas experienced were illustrated with the anonymised quotes from PLWL. The novice stage of Abby is shown in Figure 6-21.

A new persona with primary lymphoedema was developed following a similar approach to the design of the persona living with secondary lymphoedema. Research conducted with people living with primary lymphoedema built the foundation of the persona Daisy (Figure 6.22). People living with primary lymphoedema described having some symptoms since childhood: *“When I was a child I always had thick legs. I and everybody else assumed that was because I was fat. When I get into adult life. I sort of just got on with it” (Lesley)*. They explained that when swelling became more uncomfortable during adulthood, they started a pursuit for a diagnosis and a treatment. However, for some that required visiting many different doctors and unsuccessful trials: *“the doctor put me in*

diuretics for a long time, they didn't really make a lot of difference” (Sarah). Not being able to receive a diagnosis, and they could not know how to manage it: “It was just a case of nobody knew, nobody ever knew what it was. It was just I had swollen ankles all the time” (Sarah).

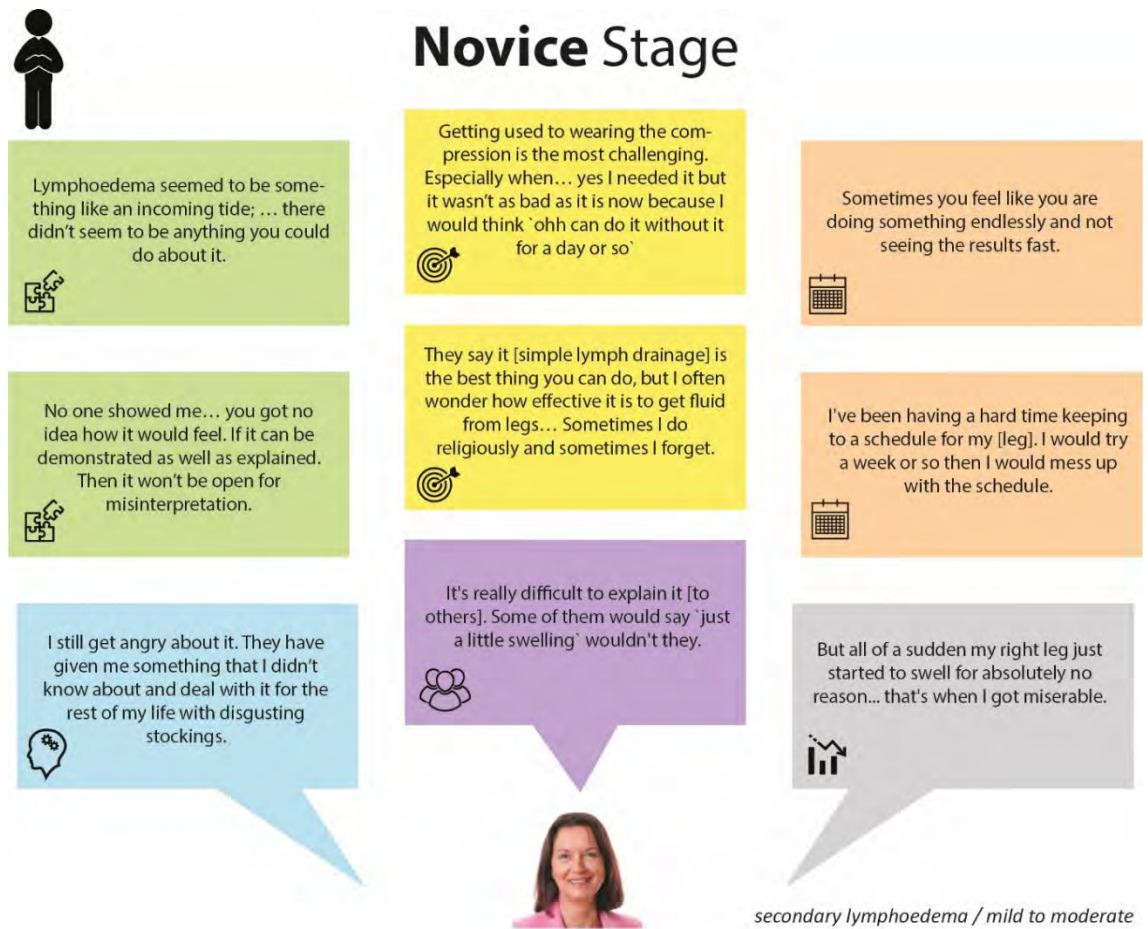


Figure 6-21 Novice stage of the Persona Abby (Secondary Lymphoedema)



Name: Daisy Sanderson

Age: 42

Family: Married.
Has two sons.

Occupation: Civil Servant

Daisy likes cooking, family gatherings and singing in the choir.

As far as she can remember, she always had puffy feet and legs. She didn't think that was a problem apart from the difficulty in finding shoes. However, her legs get bigger and painful during her pregnancy. She managed to get through, and thought it would go back after the delivery but they kept growing. Her second pregnancy was even worse. She visited many specialists, but all they suggested were diets, exercises and diuretics which weren't of any help. During a family gathering, a friend of her sister mentioned that could be lymphoedema. That was the first time she heard about it. She searched online and found a lymphoedema therapist.

Figure 6-22 Persona Daisy is living with primary lymphoedema

The novice stage of the persona Daisy was built on the research with people living with primary lymphoedema and is shown in Figure 6-23. Experience of PLWL at Experimental (Figure 6-24) and Empowered (Figure 6-25) stages shared some common themes; hence, these were created for both Abby and Daisy as similar.

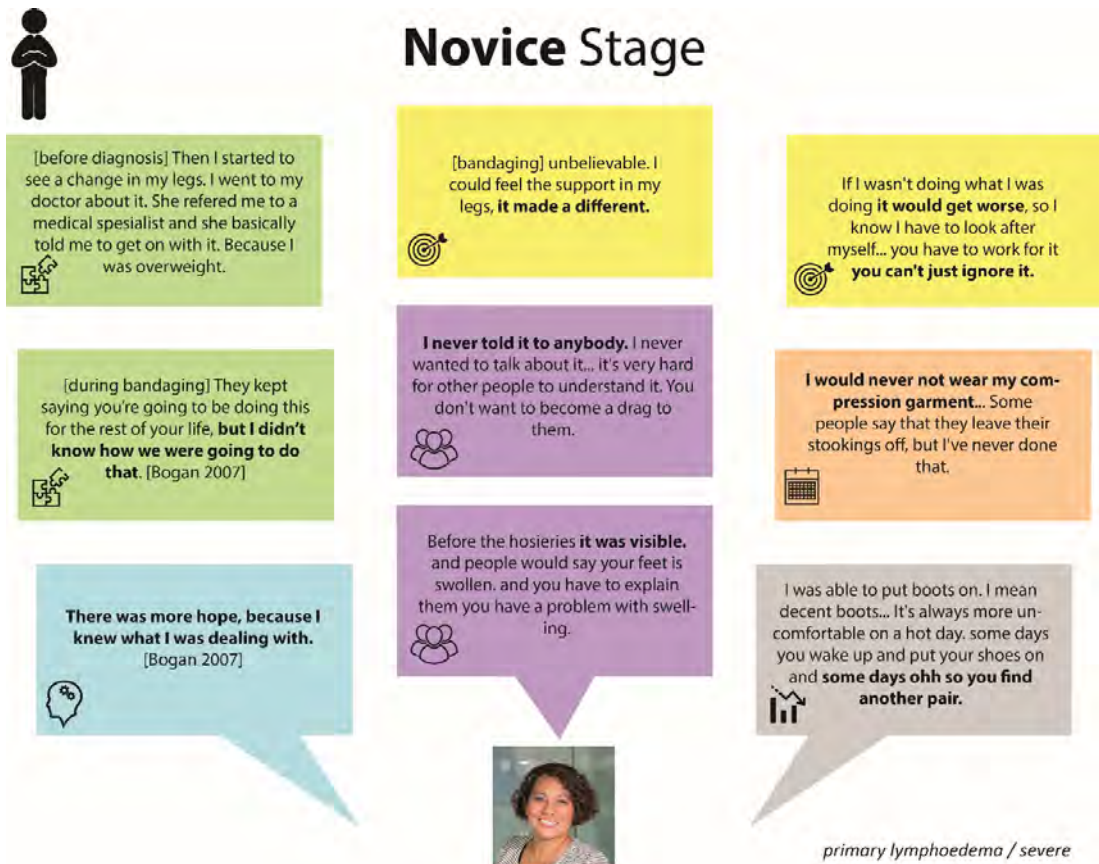


Figure 6-23 Novice stage of the Persona Daisy (Primary Lymphoedema)

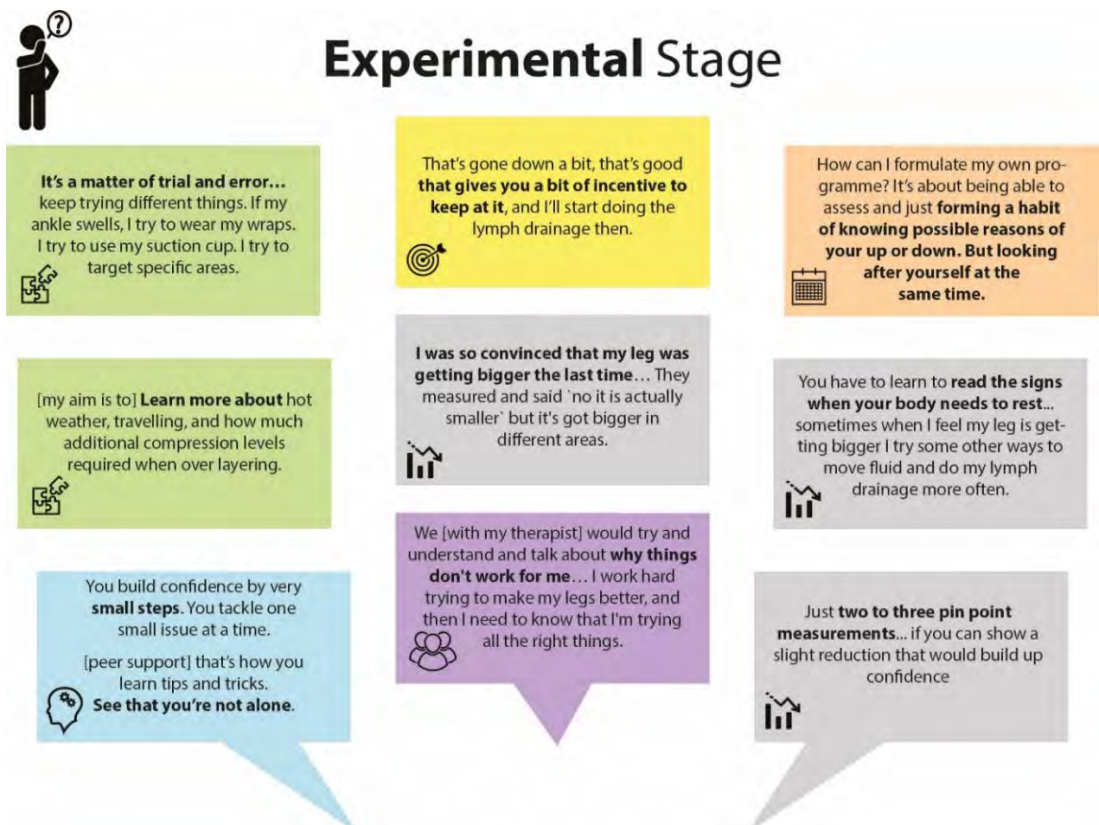


Figure 6-24 Experimental stage of the Persona Journeys

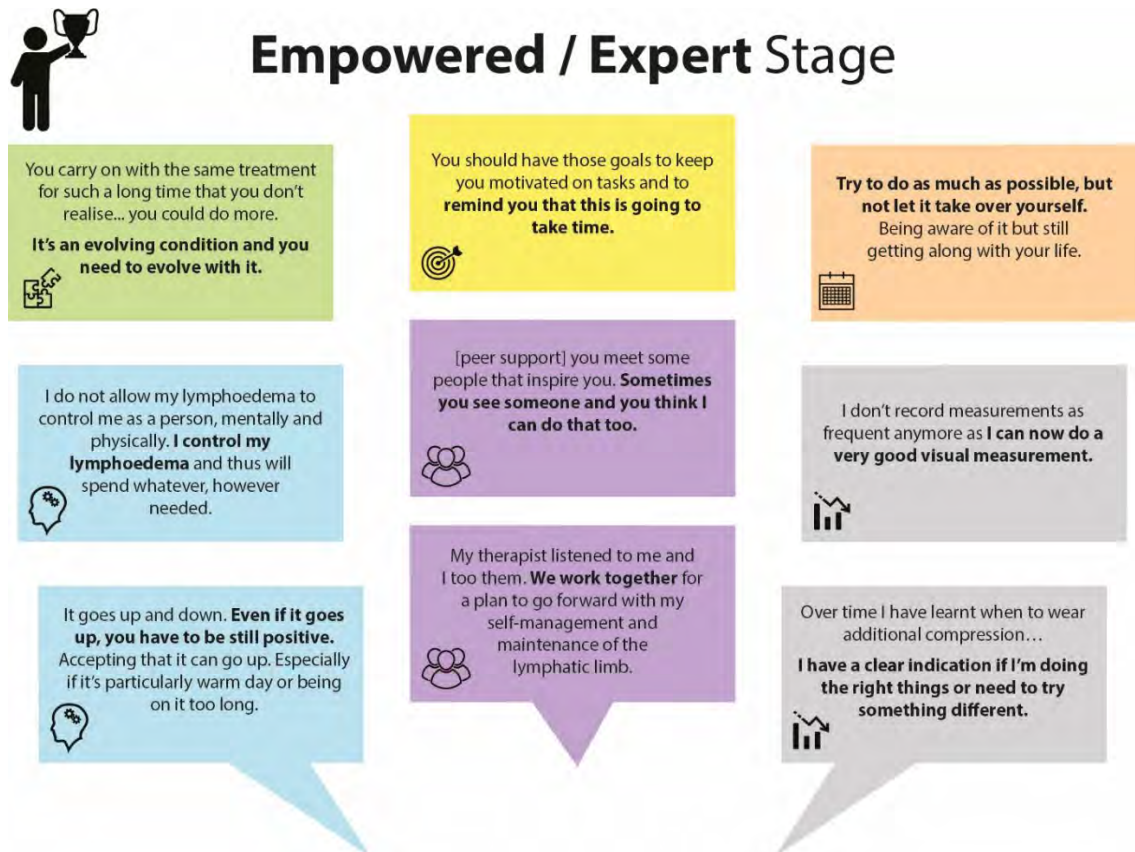


Figure 6-25 Empowered stage of the Persona Journeys

6.4 Interview with Lymphoedema Professionals

Participants of this group interview were two lymphoedema professionals. Sharon and Susan² had around 15 to 20 years of experience in providing care and therapy for PLWL. They were working together as a part of a team. In this section, the results of this interview study are presented. The persona journeys were used as probes during this study.

² Pseudonyms were assigned to participants to keep their identity anonymous.

6.4.1 Skill-Development

Participants talked about the lack of clarity PLWL experienced during the Novice stage and the importance of communication to overcome this. They explained that lymphoedema professionals were not always clear about what they say, and patients could interpret their statements differently.

It's how the patient interpreted 'wear your garment everyday'. But also the healthcare professional doesn't realise what they say. They actually mean 'I want you to wear it from morning till night'. But for the patient that means they got to wear it every day, all the time. SHARON

They described the changes in the scope of the information patients had with the increased access to world-wide-web and social media. They raised concerns about overloading patients with non-validated information: “*Who has told her all that? Has that come from a therapist, is that based on evidence? No... We burden patients a lot.*” (Sharon). They explained that online information sources could raise unrealistic expectations: “*More people come with their own ideas now. 'I've heard of this surgery that'll cure me, so can I have it?'*” (Susan). They emphasised that Experimental stage could be confusing and bring complications, if it is not experienced in collaboration with lymphoedema professionals:

We get a lot of patients who come at this experimental stage that they would say 'I've stopped wearing my garments, I don't think they are making me any better'. So we take them back to 'Well that's up to you. If you don't think that's any benefit, stop wearing them'. Then, they may say 'Oh but I had another cellulitis'. SHARON

6.4.2 Goal-Setting

Participants explained that patients at the Novice stage were usually looking for a fast and permanent solution, which was mostly not possible for a chronic and progressive condition like lymphoedema:

A lot of patients at this novice stage, they would be looking for the quick fix. It'll get better, but what you find is that it'll only put the brakes on it, so that it won't progress. But they can't see it, because they just want to get better. SHARON

They expressed that `blame` was a quite dominant feeling in their patients. Some patients were blaming their lymphoedema for their complications such as obesity. Meanwhile, some other patients were blaming themselves for having lymphoedema or cellulitis; *"they think 'I'm not managing it. What am I doing wrong?' It's blaming. I had this cellulitis, it's my fault"* (Susan). They explained that PLWL could have cellulitis no matter how well they managed their lymphoedema.

The participants explained their strategies for encouraging patients to develop intrinsic motivation for self-management. They talked about the importance of the professionals' attitude in their conversations with patients *"this is your arm your leg, we do together, and how can you manage so this is not be a burden to you?"* (Susan) instead of saying *"that's what you need to do"* (Susan). They mentioned that they had a pre-appointment leaflet for their patients to take note of what they want to talk to with their therapist. They suggested that patients' reflection on their self-management, could facilitate gaining control of their appointments:

Rather than the therapist, saying this is a measuring exercise kind of approach... This is what is important to you today. What happened in the six months? And what do we need to talk about as a priority? Which allows them to control that conversation, to be leading that discussion. SUSAN

They explained that they would not want their patients to be fixated at keeping their legs as small as possible, but to get on with their lives instead. They would want their patients to be in control and say *"I can take them [garments] off if I don't want to wear them, and I can put them back if I want to. They're really good, aren't they?"* (Susan).

The participants emphasised the importance of encouraging patients to *"get on with their lives"* (Sharon). They described the impact of *"health life, family life and work life"*

(Susan) on their lymphoedema. They noted that lymphoedema should be recognised as only a part of patients' life and it should not dominate their everyday:

Life is full of events; ok they've got lymphoedema but that lymphoedema becomes a part of your life. Not your life becomes a part of your lymphoedema problem. And I think that's the problem we've with many patients. They're fixated and healthcare professional make them fixated to change their lives. SHARON

6.4.3 Self-monitoring

The participants explained that they would not recommend that patients measure their arms/legs: “*Personally, I don't think patients should be measuring their limbs, because I want them to get on with their lives*” (Sharon). They said that measurements would change (according to the time of the day, weather, hormones and diet etc.) and taking measurements could become an obsession for some patients if not considered in relation to everyday influential factors. They talked about patients who were religiously measuring and would call the clinic when their measurements slightly increased, and may not be able to understand the whole picture, and all the influential factors causing the change in measurements:

If the patient focuses only on the measuring, then it's not the other bits that we're focusing. The weight, time of year, how they're generally, if they are in any medication. There is a whole assessment under measurement. Not just measure my arm or leg. It's the whole picture. With some patients they purely focus on that. That can cause them a massive burden. SUSAN

They said that even though measuring is part of the clinical assessment in lymphoedema, they believed that assessing prompts like pain, heaviness and sensations could be more meaningful for patients:

Possible that's [measurements] not the best way and volume can mean many different things to different people. Maybe we should be just focusing on prompts... 'How can the garment help you?'. You may find that the garment actually makes it worse, and the prompts actually decreases because of wearing the garment... So you got to weigh it up. SHARON

They explained that subjective measures were “*more meaningful over a period of time*” (Sharon). They wanted their patients to be concerned only “*if their rings are not fitting, if their socks are leaving much more of a mark, if suddenly their shoes are appeared tighter, or their sleeves are tighter*” (Susan). They suggested a self-assessment system to be able to address individuals’ needs and flag any concerns that would need a conversation with the therapist.

6.4.4 Personalisation

Participants agreed that their patients were going through stages in gaining expertise for managing their lymphoedema: “*That’s very exciting. I think you’re on to something about the stages*” (Sharon). They described the events that moved their patients back and forth, and emphasised that the journey was not one-way. They said that they would “*want the patient to be the expert whenever they can, but it’s still important to know that they will transition back, when certain aspects of the condition change*” (Sharon). Cellulitis, hot weather, weight gain and life events were mentioned by the lymphoedema therapists as examples of setbacks:

Once something gets thrown at them, you know it could be boiling hot weather, suddenly the hands start swelling, they’re back in novice. So even though they control this `yeah everything is great` they can go back. They can also go back when they’re at the expert stage. SHARON

Don’t forget lymphoedema is only one part about what’s going on with their life... If everything is ok, and that roller coaster life is ok. Now they’ll carry on and become more confident, but if something happens they go back to [pointing novice stage]. SUSAN

They also explained that in some cases lymphoedema therapists intentionally move their patients back into their transition. They mentioned that whereas some patients came to them without knowing much about lymphoedema, others brought the results of their own

investigation and many questions with them. Participants described the importance of confirming the knowledge of their patients instead of assuming they knew it correctly:

Whomever I see, I speak as if... I'll say 'I'm starting from the very beginning'. Just to check they were looking into the right sites. Even if there are some things that you have investigated. Try to confirm that they're looking at the right sites and right places and I'll bring them back down. SUSAN

Participants described that when Empowered patients visit the clinic with complex problems in their lymphoedema, they intentionally put them back to the Experimental phase by suggesting changes in their management: *"We'll say we're going to double up your garments... You're going to wear a wrap to the bed. You're going to wear the light one during the day. Then it's back to this experimental stage"* (Sharon). Participants explained how patients in the Novice stage hope for a permanent and quick solution, whilst at the Experimental stage patients started to recognise lymphoedema as a chronic condition. With the recognition of the permanence of the condition patients were *"trying all these different things to be better"* (Sharon) while their hope decreased.

Participants agreed with the differences between primary and secondary patients as referred in the two personas and their Novice stage:

From a cancer perspective, most patients nowadays are told that it [lymphoedema] could be a consequence. Whereas primary patients are often glad that they have a diagnosis. Because nobody knows what it is, so for them to be told that they have lymphoedema is a kind of relief, whereas for these patients [pointing secondary] it's a dreaded condition. So I think they are very different. SHARON

They described that sometimes their patients with mild oedema could be more fixated and concerned about their lymphoedema compared to patients with severe oedema. These patients usually had cancer related lymphoedema and they could not accept their diagnosis yet: *"Usually I find that there is this underlying psychological issue"* (Sharon). Participants also explained how the personality of the patients influence their journey and

how some people were more inclined to become experts and empowered in their self-management:

In some ways, they [participants of the study with lymphoedema] may never have been at the Novice stage, because of that type of person they are. If you look at the expert patients, they're always experts. It's almost like the DNA of the patients.
SHARON

6.4.5 Peer Support

Participants mentioned the benefits of delivering information and tips through the voices of peer patients. They also described the role of the family members, carers or partners in patients' self-management and the ways they could interpret the provided information:

Some of those family and partners will be very forceful in what they heard the patient needs to follow... `oh you can't do any of that anymore`... `we're not going to holidays anymore`. Some family members can take it to the extreme. SHARON

6.4.6 Collaborative Professional Support

Participants emphasised that as there were Novice and Expert patients, there were also novice and expert lymphoedema professionals. They described that the lymphoedema professionals' attitude and experience could make a big difference on the patients' self-management journey. They said that novice professionals would usually tell everything they know to their patients. They may not think “*about the impact of that knowledge on the patient*” (Sharon) and they may not be able to tailor the knowledge according to the stage of the patient. Whereas more experienced lymphoedema professionals would assess patient's readiness for that information and provide feasible little steps. Participants said that novice professionals could be concerned about completing tasks and telling all that was known to their patients. Whereas being able to justify their practice brought experts

the confidence to understand what the patient could deal with on that day and suggest a slower start when needed:

They may see that patient and say `You have 20% swelling and I'm giving you a flat knit made-to-measure sleeve from here to here [all the arm] and you got to wear that all the time`. Whereas we might see that patient and see that's newly diagnosed and we'll start with the lightweight. We'll say `try this couple of days a week`... We would go with a lower class lightweight garment, because that's how we start. Again, that does not happen routinely everywhere else. SHARON

Participants emphasised the importance of building collaboration with patients and encouraging their patients to gain empowerment. They talked about the impact of the way of communication could have on the patients' autonomy:

`You need to wear a garment` that statement is a very easy to say, but actually that can have absolute devastating effect on my patient... as being more experienced, I would say `This is your arm, your leg. We do this together. How can you manage this so it is not be a burden to you?`. So that's this conversation. I don't think everywhere is great to have those conversations at the moment. SUSAN

Coming to terms with having a condition was described to be related to time, patients' self-awareness and the expertise of their healthcare professionals: *"It's time more than anything and acceptance. And the recognition of what their body can and can't do to move forward. It's time and getting the right advice" (Sharon).*

They described that some patients came with their assumptions and show reluctance to work together with their therapist:

Sometimes people come at this [pointing experimental stage] and say `this is what I want` `you need to do this for me` rather than `what can we do together`. So they might already have a plan... `I can't do this I can't do that`... It's actually then actually bringing them back and saying `there is no evidence that you can't do that`. SUSAN

Referring to the My-Lymphy-Diary, participants said that accessing patients' reflection of how the last six months has been and their priorities could facilitate meaningful conversations. They described how such conversations could allow them to encourage their patients in experimenting alternative strategies and gaining control:

‘What has been the biggest issue?’ ‘I have to wear my garments for 12 hours, and really can’t cope in this heat’. That would allow the conversation to say ‘Actually it’s ok to take it off. Have you tried wearing it for 6 hours? What happens to your arm or leg then? Giving them control is really important’. SHARON

6.4.7 Summary

This section described the results of the interview study with two lymphoedema professionals. In this study, two personas (one with primary and the other with secondary lymphoedema) and their self-management journey (novice, experimental and empowered) were shared with the participants as probes. The results of this interview study are summarised in Table 6-4:

Table 6-4 Summary of the interview study with lymphoedema professionals

	Components of Self-Management Journey	Results of the Group Interview with Lymphoedema Professionals
SKILL-DEVELOPMENT	Competence Autonomy	<ul style="list-style-type: none"> - Be cautious of how the guidance might be interpreted by PLWL differently. - Do not overload PLWL with not validated information, particularly for PLWL at novice stage. - Facilitate skill-development through collaborative professional support during novice and experiential stages.
GOAL-SETTING	Autonomy Habit Identity	<ul style="list-style-type: none"> - Encourage PLWL to get on with their lives (balanced) - Encourage PLWL to be in control of their self-management (autonomy)
SELF-MONITORING	Competence Autonomy	<ul style="list-style-type: none"> - Prioritise subjective symptom tracking (such as pain, heaviness and sensations), instead of objective measures like circumferential measurements. - Facilitate PLWL’s understanding of the influential factors causing the change in their lymphoedema, instead of purely focusing on the change in measurements.

PERSONALISATION	Competence Autonomy Identity	<ul style="list-style-type: none"> - Accommodate PLWL going through stages (novice, experimental, empowered) in their self-management. People move backwards as well as forwards. It might be necessary to intentionally move patients backwards from experimental towards novice when they have misconceptions, and from empowered towards experimental when new approaches should be investigated. - Provide support tailored specific for the needs of people with primary and secondary lymphoedema, and people with mild, moderate or severe lymphoedema.
PEER SUPPORT	Competence Autonomy Psychology Identity Support Network	<ul style="list-style-type: none"> - Encourage peer support. - Provide success stories of other PLWL and explain how they achieved these. - Be cautious about the interpretation of family and friends of the provided guidance. It is not only about the patient.
COLLABORATIVE PROFESSIONAL SUPPORT	Competence Autonomy Habit Psychology Support Network	<ul style="list-style-type: none"> - Support novice lymphoedema therapists in tailoring the information they provide to PLWL at different stages of their self-management journey. - Encourage PLWL to be in control of their self-management. - Encourage PLWL to collaborate with their therapists.

6.5 Design for Empowerment Guidelines

The results of the iterative research presented in this thesis (chapters 4, 5 and 6) have been synthesised to propose guidelines for design to support patient empowerment (Table 6.5). As evidenced from the presented results of this PhD, patient empowerment is a journey and people's needs are changing with increased expertise in self-management. Empowerment requires experiential learning and the transfer of power in decision-making to the patient, yet that could be overwhelming for a novice who has been recently diagnosed (or lacking motivation, support or competence in their self-management). While, the support approaches appropriate for someone at the novice stage is not adequate to facilitate empowerment. The 'Model for Empowered Self-Management' (section 5.3.3) has presented the characteristics of the stages PLWL go through while gaining

empowerment. The `Design for Empowerment Guidelines` introduced in this section present the stage-based support strategies to facilitate this journey.

When the results of the studies analysed all together, the six categories of design strategies to support self-management have been recognised to have some overlaps. Personalisation as a design strategy became integral for all the involved strategies and guidelines. `Peer support` and `collaborative professional support` strategies shared common themes. The results of the studies with PLWL and lymphoedema therapists have been revisited and analysed together, which lead to revisions of these themes. As a result of this analysis, four main strategies to design for empowered self-management have been defined: 1) Skill-development for proactive problem-solving, 2) Self-monitoring for well-informed decision-making, 3) Personalised goals for integrated habits, and 4) Collaboration for wellbeing and adaptation. Guidelines for design for empowerment are presented in Table 6-5.

Table 6-5 Design for Empowerment Guidelines

	NOVICE	EXPERIMENTAL	EMPOWERED
Skill-development for proactive problem-solving	Start with cornerstones of self-management, and by their hands-on and multisensory demonstrations.	Encourage broadening the self-management regime gradually by learning new strategies.	Encourage ongoing experiential learning for continues management of the evolving condition.
<i>Competence</i>	Explain the physiology of the condition and the underlying principles of management strategies, (why & how these strategies could help).	Encourage reflective observations and active experimentations on influential factors (possible triggers and management strategies) in collaboration with the healthcare professionals.	Refresh information about management strategies and possible triggers.
<i>Autonomy</i>	Avoid information overload and not validated sources of information. Be cautious about the ways such advice might be misinterpreted.	Encourage accessing alternative sources of information and the ones shared by peers living with the condition.	Encourage the use of alternative sources of information and staying up to date about new developments.
<i>Habit</i>			

	NOVICE	EXPERIMENTAL	EMPOWERED
Self-monitoring for well-informed decision-making <i>Competence</i> <i>Autonomy</i>	<p>Explain the realistic outcomes/expectations from self-management strategies (how long it takes to see results and how these results look/feel).</p> <p>When symptoms monitored to be increasing despite self-management: 1) remind about the realistic expectations, 2) mention the influence of possible triggers, 3) signpost to psychological support and guidance.</p>	<p>Encourage monitoring the influence of self-management strategies and potential triggers on symptoms.</p> <p>When objective self-monitoring agreed to be beneficial, be cautious about not encouraging obsession with quantifying the condition. Facilitate self-monitoring for meaningful experiential learning and for understanding: 1) when professional help should be sought, 2) to observe the effectiveness of self-management strategies, 3) how to adapt these strategies when needed, 4) influence of possible triggers and out-of-routine activities.</p>	
	<p>Encourage subjective self-monitoring (sensations) for developing awareness of the symptoms, possible on-sets of fluctuations and complications like cellulitis.</p> <p>Propose a roadmap to access support and an action plan for supporting the decision-making in case of possible complications and emergencies.</p>		
	NOVICE	EXPERIMENTAL	EMPOWERED
Personalised goals for integrated habits <i>Autonomy</i> <i>Habit</i> <i>Identity</i>	<p>Understand personal self-management habits and aspirations.</p> <p>Encourage building daily self-management routines one-step-at-a time for practicing cornerstones of self-management that align with individual habits and aspirations.</p>	<p>Encourage setting self-management goals and accommodate personal priorities.</p> <p>Facilitate integrating self-management to everyday life with the broadened strategies, in a balanced way by tailoring routines according to personal goals.</p> <p>Understand out-of-routine habits and encourage having self-management plans for such occasions.</p>	<p>Understand and support current self-management habits and personal goals.</p> <p>Encourage self-management to become a part of life, but not to dominate it.</p> <p>Encourage people to feel and be in control of their own self-management.</p>
	<p>Provide support tailored specific for the needs of people with primary and secondary lymphoedema, and people with mild, moderate or severe lymphoedema.</p>		

	NOVICE	EXPERIMENTAL	EMPOWERED
Collaboration for wellbeing and adaptation <i>Competence</i> <i>Autonomy</i> <i>Psychology</i> <i>Identity</i> <i>Support</i> <i>Network</i>	Encourage access to hands-on professional lymphoedema support.	Encourage collaborative exploration of management strategies and possible triggers with healthcare professionals.	Where possible, facilitate continuous follow-up appointments to stay motivated and informed about managing lymphoedema.
	Understand personal barriers against self-management, the psychological and social state. Suggest a roadmap for when and how to access professional support.	Facilitate peer support for sharing suggestions and tips about self-management.	Facilitate peer support for sustained motivation and to be informed about new developments.
	Encourage peer support for `normalising` the condition and for psychological support	Encourage expression of personal lymphoedema stories to support the construction of identity with lymphoedema.	Encourage expression of chronic condition stories to affirm identity with lymphoedema.
	Be cautious about how family and friends might (mis)interpret the provided information.		<i>Products and systems could be designed to look more conspicuous to start conversations and to spread the word about lymphoedema.</i>
	<i>Products and systems should be designed in a way that minimises their perception as medical devices. These should be as discreet as possible.</i>		
	Share success stories of people living with lymphoedema.		

It was important to present the model and the guidelines in a way that is applicable by designers of the future self-management support systems, healthcare providers and anyone who is willing to support someone with this chronic condition. These guidelines were adapted and linked with the characteristics of the related stages and with examples of how the stage specific support could be implemented in design or during conversations with PLWL. This is presented as a booklet of `Design for Empowerment` in Appendix G.

At **Novice** stage, PLWL need hands-on and multisensory demonstrations of what lymphoedema is and what that implied for the individual. Understanding of the socio-psychological state of the individual and how they perceive the barriers against self-

management would be helpful to be able to signpost them to further professional support. Evidence-based management strategies (the cornerstones of lymphoedema self-management) should be prioritized with demonstrations on how and why these could be helpful. Information overload should be avoided at this stage. Viable expectations from the strategies should be set, in terms of when the results of self-management could be experienced, and how would that look and feel. Sharing experiences of other PLWL and their success stories would be helpful while explaining how self-management could help them and to `normalise` the condition, though careful attention needs to be paid to the content of the delivered information through such mediums. At this stage, precautions should be taken about alternative and online sources of information to avoid information overload and misunderstandings. Lymphoedema professionals and evidence-based research should be the primary source of information at this stage. Products and systems should be designed in a way that minimises their perception as medical devices and these should be as discreet as possible.

Experimental Stage is where PLWL should be supported to gradually broaden their self-management strategies and develop understanding of the influence of these strategies to their symptoms. This is the stage where individuals start to have increased autonomy and adapt their self-management programmes. Peer support would be helpful at this stage for sharing suggestions and tips. Developing awareness of the symptoms and self-monitoring should be supported to allow observing the effects of these strategies and possible everyday triggers, and for making well-informed self-management decisions. This should be supported by encouraging reflective observations on their widening self-management routines. Objective self-monitoring of the swelling could be helpful in this stage, to observe the influence of management strategies and potential triggers on the symptoms, and be able to adapt management accordingly. Alternative sources of

information and management strategies would be helpful at this stage, since the individual is better able to assess their potential influence to the symptoms. At this stage, encouraging individuals to reflect on their goals and aspirations is important to support them integrate their self-management to everyday life in a balanced way. Lymphoedema professionals work as collaborators with PLWL at this stage, for finding best self-management strategies, and routine that works for the personal needs and goals of the individual.

Empowered stage is when PLWL are able to manage their condition in a confident and balanced way that is integrated to their everyday life. Support in this stage focus on helping individuals not to have relapses and encouraging self-monitoring to be able to recognise fluctuations, and when management strategies are not as effective as they used to be. Support could help them to stay up-to-date in terms of new developments and continue updating and refreshing their management strategies. At this stage, PLWL could be patient advocates, and products and systems could also aim being a tool for increasing the awareness about lymphoedema. `Patient as the expert` should be acknowledged at this stage and their experience should lead the self-management decisions.

6.6 Chapter Summary

This chapter presented the exploration of the design strategies to support the lymphoedema self-management. First, the design of the cultural probe was described and the results of the cultural probe study conducted with PLWL were presented. Then, the design of the persona journeys was explained and the results of the group interview conducted with lymphoedema professionals were demonstrated. Finally, all the insights gained from the presented research was brought together to form the `Design for Empowerment` guidelines (Table 6.5 and Appendix G). During their journey towards

empowerment, PLWL were going through stages and their needs were changing. Providing stage specific support was critical to facilitate this empowerment.

In the following Discussion Chapter, the implications of the contributions to knowledge presented in this thesis are discussed by considering their limitations and implications. These are contextualised in relation to the existing literature on patient empowerment and design.

Chapter 7 Discussion

How might we design to support the empowerment of PLWL in their self-management?

Answer 1: Self-Management support should be designed to adapt to changing needs of PLWL, while they gain empowerment in their self-management. (Sections 7.1, 7.2, 7.3)

Answer 2: Designing with `empowered patients` as participants, and `design probes` as research methods (to explore their past, present and future) were effective in exploring the needs of PLWL. (Section 7.4)

The answer to the main research question of this study is two-fold. The first answer is related to design as an `outcome` (design as a noun), and how to design products and services to facilitate the empowerment journey. The second answer is related to design as a `process` (design as a verb), and discusses working with `empowered patients` as research participants and methods in facilitating an empowering design process. The following sections discuss these answers in context, by recognising the limitations and expanding on their implications:

- **7.1. Empowerment in Lymphoedema Self-Management:** The meaning of empowerment in lymphoedema self-management, in relation to the term as previously described in the literature.
- **7.2. Model for Empowered Self-Management:** The presented `Model for Empowered Self-Management`, in relation to other self-management models in the literature.
- **7.3. Design Guidelines for Empowerment:** Potential implications of the presented design guidelines for empowerment in lymphoedema self-management.
- **7.4. Implications of the Methods for Design Research:** The first section discusses literature review as a data collection method in design research. The second section looks into the experience of designing with `empowered patients` through the use of design probes in exploring their past, present and desires for future.

7.1 Empowerment in Lymphoedema Self-Management

For an acute medical illness, the spectrum of physical recovery is usually clear with the ultimate success defined as full recovery. However, chronic conditions do not have a cure and require life-long self-management. Since recovery cannot be the aim, the meaning of successful self-management could be different for a patient and a clinician. In the literature, `success` in self-management was usually used to imply improved health outcomes, and patient's increased adherence to prescribed self-management (Grady and Gough, 2014, Nakagawa-Kogan et al., 1988). However, for the participants of this study with lymphoedema, successful self-management has been beyond health outcomes and complying with self-management. That also corresponded to previous studies on how people living with chronic conditions perceived successful self-management themselves (Anderson, 1985, Anderson and Funnell, 2000, Bodenheimer et al., 2002). Dixon et al. (2009) reported that successful self-management meant being compliant only for people living with chronic conditions that were less active/engaged in their healthcare. Whereas for active participants successful self-management was "*about being in control*" (Dixon et al., 2009). Similarly, in lymphoedema, Jeffs et al. (2016) presented that many PLWL described being in control and "*taking ownership*" as a prerequisite for successful self-management. Understanding the meaning of successful self-management for PLWL has been important for this research, because support systems should be designed to help individuals be successful and achieve their goals. The results of this study brought forward `empowerment` in self-management as a measure of success and an objective for PLWL. The term `empowerment` is chosen because: 1) it aligns well with the participants' definition of successful self-management, and 2) the term is frequently used in the literature, as well as by private and public healthcare organisations. In this section, the

meaning of empowerment will be discussed in relation to the `patient empowerment` concept as represented in the literature.







In healthcare, `empowering` people for shared decision-making about their care was identified as a key aspect by NHS (2019), and NMC (2018). Patient empowerment has been set as an ultimate goal by many healthcare organisations, for increased quality of life for patients and for sustaining the limited resources of the health services provided. In post-COVID world the public healthcare services are more stretched and challenged. Increasing number of people living with chronic conditions, and economic challenges accelerate the pressure on health organisations. This in turn increase the demand from the patients to adapt and take the decision-making responsibilities for self-managing their conditions with as little professional support as possible even so more quickly. This quick change in decision-making responsibility can be promoted and misinterpreted as empowerment. In post-COVID world this demand has been growing and makes understanding the meaning of empowerment even more prominent.

In the literature, going beyond the traditional health outcomes, and assessing `patient empowerment` as a construct of healthcare was acknowledged, though there was not one widely accepted definition (Aujoulat et al., 2007, Barbosa et al., 2021, McAllister et al., 2012, Pekonen et al., 2020, Payne et al., 2013, Samoocha et al., 2010, Schneider, 2019). Previously the assistive health technologies that were advertised to be `empowering` their users, has been criticised to have potential to oppress and `dis-empower` their users by stigmatising, leaving them alone to self-manage, and making them feel more anxious and pessimistic about their condition (Schneider, 2019). Wyatt et al. (2010) criticised that `patient empowerment` initiatives were fundamentally aiming to decrease the financial burden of chronic condition care, and were usually build on the false assumptions that increased knowledge and choice, would lead to increased empowerment

and health. Beyond patient's knowledge and expertise, a holistic approach considering the person's social context was emphasised to be required for 'empowerment' (Harris et al., 2010). This is corresponding with the results of this thesis, in which not only competence, autonomy and habit aspects of self-management are taken into consideration as constructs of empowerment, but also the psychology, identity and support network. The meaning of 'empowerment' for PLWL is presented in Table 7-1.

'Patient empowerment' as defined in the literature have some similarities with the meaning of empowerment proposed in Table 7-1. However, previous definitions focussed on some of the components only and were missing key aspects that have been highlighted by the participants of this study. 'Control' and 'power' were key elements for 'empowerment' and frequently mentioned in the literature. WHO (1998) described patient empowerment as gaining "*greater control over decisions and actions affecting their health*". However, as Hewitt-Taylor (2004) said 'empowerment' was more complex than simply passing over the 'power' of decision-making from healthcare providers to the patients. Aujoulat et al. (2007) discussed that self-management behaviour could only be perceived as an outcome of empowerment, if that was self-determined as a goal by the patient. However, such self-determination also meant that the goals of patients could be different from the advice of the healthcare providers (Aujoulat et al., 2007). The dilemma was evident when empowered individuals chose not to comply with their self-management regimes. However, patient empowerment definitions in the literature did not compromised both autonomy (having control over self-management decisions) and health behaviour (the actual practice of self-management) together.

Table 7-1 Empowered Self-Management (adapted from Table 5-6 Model for Empowered Self-Management- Empowered Stage)

EMPOWERED SELF-MANAGEMENT				
<div>COMPETENCE</div> <div></div>	<div>I can manage my condition despite fluctuations.</div> <div>I always look for new strategies to manage better.</div>			
<div>AUTONOMY</div> <div></div>	<div>I am managing my condition because it's important for me, it corresponds to my goals and is a part of my life.</div>			
<div>HABIT</div> <div></div>	<div>Living as 'normal' as possible with a chronic condition</div>	<div>Self-management is a part of my everyday life.</div>		<div>Living with a chronic condition</div>
		<div>I adapted my self-management to integrate it to my everyday life. I don't let my condition to take over my life nor to my symptoms to creep.</div>	<div>I adapted my everyday life so that I can manage my condition.</div>	
<div>PSYCHOLOGY</div> <div></div>		<div>I get on with my life as normal as possible.</div>	<div>I accept my condition. Thanks to my self-management, I can live the life I cherished.</div>	
<div>IDENTITY</div> <div></div>		<div>I do not limit or change my life because of my condition. I do not let my condition to identify me, nor my symptoms to creep.</div>	<div>My condition is a part of my identity. I prioritise managing my condition. I want others to know about my condition and self-management.</div>	
<div>SUPPORT NETWORK</div> <div></div>	<div>I feel supported and well connected.</div> <div>I work in collaboration with my healthcare professionals to better manage my condition.</div>			

Existing empowerment definitions usually focus on patient's increased 'power' in decision-making, with the expectation of that decision being in favour of adhering with certain self-management regimes. However, the responses of the study participants in this thesis have highlighted some tensions between self-determination and adherence approaches. Empowerment according to the participants of this study involved the everyday clashes in balancing 'living as normal as possible' and 'living with a chronic condition' (Table 7.1). All participants agreed on the importance of integrating self-management into their everyday life. However, that could imply various adaptations. For some participants, everyday self-management was achieved through drastic changes to lifestyle, whilst for others it was achieved by adapting the recommended self-management. The latter was less talked about, because this could be (and usually is) labelled (and sometimes mislabelled) as non-adherence to self-management. In this study conversations about why and how sometimes the 'empowered' participants of this study were not following their self-management as 'instructed' revealed an 'adaptation' that was actually led by their empowerment. They were confident about their strategies for low-risk adaptations and getting back on track when needed. Empowered participants of this study found a fine balance in managing their symptoms, while continuing the behaviours and activities that they valued high for a meaningful life. However, they were also concerned about the judgement of healthcare professionals about their adaptations to the prescribed self-management regime. That was evident especially when they were talking about eligibility criteria for surgical procedures, which necessitated adherence to self-management. During interviews, even though participants were not inquired about their adherence, they explained the extent to which they followed their self-management and described a self-evaluation of their health behaviour. During observations and informal interviews, cases where patients concealed their shortfalls in compliance to their self-

management were observed and mentioned. This could be problematic, especially for building an honest and collaborative `support network`. `Empowered patient` is the decision-maker, and compliance approach is unfit at that stage. However, increased decision-making responsibility at earlier stages of the self-management journey could be overwhelming and risky. Adaptations to the self-management should be considered cautiously and in context depending on the severity of the condition and the stage of the individual in their self-management. According to study participants, such adaptations in self-management routines have been achieved as a result of a maturity in their empowerment journey. Looking into ways to adapt self-management prior to reaching a certain level of experience could have negative consequences. Hence, in this study the meaning of empowerment is described holistically through all the contributing constructs and as journey, rather than a state of increased decision-making. Successful self-management have different meanings for patients at different stages of their empowerment journeys.

Previously in the literature, in addition to the increased decision-making, patients' cognitive and physical capacity, and their knowledge were frequently mentioned while defining patient empowerment (Pekonen et al., 2020, Fumagalli et al., 2015). All participants of this study agreed on the importance of being physically and cognitively able to manage symptoms. In addition, the participants also highlighted their ongoing quest for new developments. Participants described lymphoedema as an evolving condition requiring continuous exploration of new strategies. Even after practicing a self-management routine that worked well for a long-time, that regime could become ineffective over time. Participants explained the management strategies that they had found thanks to their own proactive inquiry and research. Hence, for the participants, empowerment was not only having control over the options suggested by their healthcare

providers, but also an ongoing and self-determined endeavour for new alternatives. In the literature, healthcare professionals' role for patient empowerment was frequently emphasised, mostly as patients as empowered by the support of healthcare professionals (Palumbo, 2017, Fumagalli et al., 2015, Pekonen et al., 2020). Holmström and Röing (2010) highlighted the ways patients were empowering themselves including education programmes, internet and support groups. Participants of this study frequently described their own proactive inquiry and the help of their support network for their empowerment.

Previously, identity and psychology components were usually overlooked in patient empowerment definitions. For instance, Fumagalli et al. (2015) reviewed patient empowerment in relation to the surrounding terms of patient `engagement, enablement, participation, involvement and activation`, and proposed the following definition:

Patient empowerment is the acquisition of motivation (self-awareness and attitude through engagement) and ability (skills and knowledge through enablement) that patients might use to be involved or participate in decision-making, thus creating an opportunity for higher levels of power in their relationship with professionals. (Fumagalli et al., 2015)

Their definition highlighted patients' motivation, ability and power, yet did not mention the actual behaviour (habit) nor the psychological or sociological aspects related to having a chronic condition. Such socio-psychological constructs of living with a chronic condition were highlighted as undervalued in the literature previously (Aujoulat et al., 2008, Arnold et al., 1995). Aujoulat et al. (2008) asserted patient empowerment as a `personal transformation`. According to their study this transformation was not always through gaining `control` and `power`, although these terms were frequently aligned with patient empowerment in the literature. They presented that one of the ways that patients gained empowerment was by “*letting go by relinquishing control*” to come to terms with living with the condition and rebuilding their identity with it (Aujoulat et al., 2008). For the participants of this study, such socio-psychological constructs were integral parts of living

with a chronic condition. Participants described the influence of the visibility of their conditions to their everyday life. While some perceived hiding their condition necessary but also a limitation for their life, for others that was their decision that they were content about to 'live as normal as possible'. For some PLWL empowerment was achieved by being comfortable with the visibility of their lymphoedema in social life, for others by being able to adapt and effectively hide that. These were consistent with the dilemma of 'gaining control' as described by Aujoulat et al. (2008) where rebuilding ones identity with the chronic condition could also mean letting go some of the control.

Empowerment as presented in this thesis comprehends the habitual and socio-psychological determinants besides autonomy and competence aspects. Being in 'control' and having 'power' in self-management could have different meanings for people living with chronic conditions. In this study, it was shown that *'living with a chronic condition'* with an emphasis on 'being a patient' was not the only way to be empowered in self-management. *'Living as normal as possible with a chronic condition'* and safe adaptations to the self-management could also lead to empowerment. Yet a certain level of experience and self-management skills were necessary to achieve this in a safe way. Lymphoedema self-management is a journey, in which individuals should be supported in making gradual progress. Even though 'empowerment' has been defined as the goal in self-management, aiming a jump to the empowered stage could be problematic. Empowerment is multidimensional and requires readiness to make well-informed self-management decisions. Hence, the stages that lead to empowerment is important, and the journey required tailored support that is timely and appropriate for the individual. In the following section the stages towards patient empowerment and this journey is elaborated in relation to the existing models.

7.2 Model for Empowered Self-Management

The research presented in this PhD showed that PLWL experienced lymphoedema self-management as a multidimensional journey. The components and stages of this journey towards empowerment in lymphoedema self-management were presented in Table 5-6. The characteristics of three main stages: novice, experimental and empowered stages were distinguished within this journey. Individuals' needs were different depending on which stage they were at and should be supported accordingly to facilitate their empowerment. The stages and components described in this model were drawn from the recurring comments of the participants in this study. It is important to note that, the stages shown in Table 5-6 should not be considered as simplification of the personal self-management experiences into one typical journey. The journey was not always a linear progression either, as would be expected from any human experience. Lymphoedema journeys would be as diverse and unique as the individuals experiencing these. As Zimmerman (1995) discussed, 'empowerment' was different depending on context, populations and time. In this study, empowerment is investigated particularly for PLWL and the changes to the meaning of empowerment over time is proposed. This study brought the theories about human behaviour and the voices of PLWL together to find better ways to design for them. This categorisation of stages allowed for the transfer of these rich lived experiences into actionable guidelines for designers, who will be designing the next generation support systems. Understanding the stage specific needs of individuals is important to personalise and tailor the systems accordingly. This study attempted to contribute to the design of evolving systems that could match the provided support to the changing needs of individuals in their empowerment journey.

Previous patient empowerment models were consistent with the findings of this study, yet as far as the literature search evidenced there was not one model that considered all six components of the self-management experience together (competence, autonomy, habit, psychology, identity, support network). The literature review evidenced only one other model describing the self-management experience specifically for lymphoedema (Jeffs et al., 2016). Their model presented a journey and distinguished emotions, actions, knowledge required by PLWL besides the actions of lymphoedema professionals (Jeffs et al., 2016). When models for chronic condition self-management in general (not for one particular chronic condition) were investigated, two models were found to be cited frequently and used in clinical practice: Patient Activation Model (Hibbard et al., 2004) and Patient Enablement Instrument (Howie et al., 1998). These were questionnaires that were used in healthcare practice for capturing some aspects of patient empowerment (McAllister et al., 2012). Patient Enablement Instrument focuses on evaluating the perceived control over the chronic condition management (Howie et al., 1998). The Patient Activation Model assesses individuals' knowledge, skills and beliefs about being active in their self-management, however in this model socio-psychological components were not included (Hibbard et al., 2004). Another model called Patient Health Engagement (Menichetti & Graffigna, 2016) included the psychological aspects of having a chronic condition, yet overlooked identity and social network components. The Patient Health Engagement model was in agreement with the model presented in this thesis, and had three stages, yet the mid stage was described as 'formally adherent' and did not mention the 'experimental learning' and 'adaptation' expressed by the participants of this study.

On the other side, similarities between the presented 'Model for Empowered Self-Management' for lymphoedema and the previous ones on self-management in general, suggested potential for this study to contribute to other chronic conditions beyond

lymphoedema. Previously, stages in terms of patient activation (Hibbard et al., 2004) and engagement in healthcare (Menichetti & Graffigna, 2016) were described as a result of studies conducted with people with other chronic conditions. A transitional process towards empowerment was evident in chronic condition self-management, though the particularities of that experience could differ depending on the chronic condition. The model presented in this thesis describes the journey to empowerment in lymphoedema self-management. The presented model has potential to contribute to the design for other chronic conditions, yet that should be investigated through future research.

The results of this study suggested that the self-management journey was also influenced from the severity of the chronic condition. However, that was not fully explored in this study, because of not being able to conduct participant sampling allowing diversity in the severity of the condition. The participants of this study had all mild-to-moderate lymphoedema. Previously in the literature, links between the severity of the illness and the patients' preference and availability of choices were suggested. According to Salmon & Hall (2004) the less acutely ill the patient was, the more option they would like to have. Future work should further elaborate the influence of the severity of the chronic condition to the empowerment of the patient and their self-management experience.

7.3 Design Guidelines for Empowerment

Design guidelines for empowerment are presented in Table 6.5 and shows the stage-specific strategies to support the self-management journey of PLWL. In this section, these guidelines and their potential implications for future are discussed in relation to the literature.

Increased power in decision-making was agreed to correlate with the patient empowerment concept (WHO, 1998, Fumagalli et al., 2015). However, having more

options and control over decisions were not necessarily preferred by the patients, or presented better results for them. According to Angelmar and Berman (2007), when more options were presented to the patient, they required to spend more self-regulatory resources to make decisions, which led to difficulty in self-management. Botti and Iyengar (2006) emphasised that healthcare related decisions were not only difficult because of their cognitive load, but also the emotional burden of having trade-off options. These studies support the findings of this research and highlighted the importance of the timeliness of increased autonomy and decision-making in self-management. Patient empowerment requires room for experiential learning and the transfer of power in decision-making to the patient, yet this could be overwhelming for someone at the novice stage. Though, support strategies that are effective for `novices` (such as a fixed and simple self-management regime), could become detrimental when moving towards `empowered stage`. Hence, timely change in the provided support is needed to allow individuals to develop empowerment in their self-management. One of the main contributions of this thesis is specifying the right time for facilitating the gradual transfer of decision-making to the patients.

Self-monitoring for well-informed decision making was one of the suggested design approaches in the guidelines, and was previously discussed in the literature for people living chronic conditions including diabetes and hypertension (McBain et al., 2015b). However, unlike such chronic conditions where self-monitoring was encouraged as a part of the self-management regimes; in lymphoedema no professional support for self-monitoring was available for the study participants. In lymphoedema, symptoms could not always be easily recognised and may not be correlated with the known factors. Hence, despite being practiced among PLWL, self-monitoring was not recommended as a part of lymphoedema self-management by healthcare professionals. One of the ways to self-

monitor lymphoedema was to take circumferential measurements from the affected limb. The literature review of the lymphoedema experience identified `self-monitoring via measurements` in only one article among the systematically selected 31 studies (Bogan et al., 2007) (Chapter 4). However, four of the study participants (total number of participants with lymphoedema N=10) described their long-term self-monitoring experience and how they kept track of their circumferential measurements. Lette et al. (2007) asserted that healthcare professionals were not encouraging PLWL to measure and keep track of their lymphoedema. This PhD study shows that one of the reasons for such reluctance was not to cause any unnecessary obsession and anxiety on the patient. Lymphoedema could fluctuate for numerous reasons within the day. Self-monitoring is beneficial only if the individual is at a stage where they can interpret these changes and make well-informed decisions accordingly. Timeliness of such interventions is essential depending on where the individual is at their journey towards empowered self-management. In the literature, this change in self-monitoring needs of PLWL was not mentioned previously.

Even though self-monitoring was rarely mentioned in the studies describing the lived experience of PLWL and documents to inform patients, a variety of ways to self-monitor was suggested by previous researchers working on designing systems for PLWL. These include tape measurements of the circumference (Galiano-Castillo et al., 2016), water displacement for volumetric change (Lette et al., 2007), bioimpedance for percentage of fluid accumulation (Ridner et al., 2014b), and subjective symptom assessment (Fu et al., 2016b). These studies tested their final systems with PLWL. However, PLWL's involvement during the design of these systems was either limited or undocumented. Hence, despite good intentions, it is not clear the extent to which these systems have been developed in response to the needs of PLWL. Moreover, these systems were designed considering some of the components of self-management in isolation, potentially

underestimating the influence of others, especially the psychological and social components. In this study, self-monitoring approaches were investigated with PLWL and lymphoedema professionals. The results presents that subjective self-monitoring such as developing awareness of the changing symptoms and sensations are helpful at all stages. However, objective self-monitoring such as tracking tape measurements of the circumference can be distressing for PLWL at Novice stage and unnecessary for the ones at Empowered stage. Objective self-monitoring is best suited for the needs of individuals at the Experimental stage, when it is in line with exploring triggers and alternative management strategies.

In this thesis, the different support needs of PLWL depending on their level of empowerment is presented. Hence, it might be hypothesised that novice and empowered patients may be using support systems differently. Previously in the literature, the difference in use behaviour between novices and experts (in terms of their expertise in their chronic condition self-management) was mentioned only to a limited extent. Mamykina et al. (2010) reported on their study with two different groups of people living with diabetes, on a mobile application. The first group was recently diagnosed with the condition and their use of the mobile application was focused at the problem-solving features of the application (Mamykina et al., 2010). They recruited the second group of participants who had diabetes for over 10 years, to primarily generalise their findings for a broader group and they used the same technology, yet they observed that this second participant group engaged with the application in a drastically different way (Mamykina et al., 2010). Their participants experienced in diabetes used the application to record personal stories, which was not always relevant to diabetes. Mamykina et al. (2010) asserted that these participants expressed their stories to affirm their identity as positive, to reassert their competence in diabetes management and to maintain their pre-diabetes lifestyle. Similarly, the

participants of this study were experienced in their self-management and utilised the reflective writing features of the My-Lymphy-Diary more than the involved everyday problem-solving elements. However, the differences in the use behaviour of individuals at the novice and empowered stages were not fully investigated in this study, and would be the subject of future work.

Even though the influence of expertise in chronic condition self-management systems was not frequently mentioned in the literature, there were many studies about the influence of the users' expertise in general for using digital systems. The difference between the usage behaviour of novices and experts (in terms of their expertise in using the evaluated system or their computer literacy) were clearly defined in the literature. Popovic (2000) presented the differences in novice and expert cognitive structures (knowledge acquisitions, knowledge types, uncertainty, intention, action etc.) while interacting with a system. Their model focused on the cognitive processes and highlighted the importance of designing to facilitate the journey from `novice to expert usage` (Popovic, 2003). In another study, Cockburn et al. (2014) described that graphical user interfaces were usually designed for novice users, with the aim to facilitate their ease of learning. Ease of learning was desirable, but in the long-term it could lead the use of the software in inefficient ways and hinder the transition towards expert usage, and consequently ways to facilitate change from novice to expert modes were suggested (Cockburn et al., 2014, Scarr et al., 2011, Fischer, 2001). Another area the stage based design approach was discussed was gamification. Chou (2019) described four experience phases for gamification: "Discovery, Onboarding, Scaffolding, and Endgame". In this process based approach to gamification Chou (2019) highlighted that these should be considered as four different products to be designed for the evolving needs of the user. Despite not being related to chronic condition management, these studies indicated examples of other systems where the benefits of

adapting the system to the changing needs of their users with their increased expertise was evidenced.

Self-management journey is dynamic. The Model for Empowered Self-Management should not be considered as a prescribed stage-by-stage process that everyone moves forward through. Some could start from the experimental stage and relapse because of other life events. The described six components could also not be at the same stage, or these may not move simultaneously. A system that was pre-programmed to gradually change the support without re-assessment would overlook any fall-backs. Hence, an adaptive system, which could continuously assess and evolve accordingly, would be necessary to suffice these changing needs.

With the development of artificial intelligence, adaptive systems were proposed to dynamically change the interface to match the needs of the users (Miraz et al., 2021). Miraz et al. (2021) reviewed adaptive systems and the ways these could better accommodate users with varying levels of knowledge, experience, skills, emotional status and sensory deprivation. They asserted that user performance could increase with systems enabling dynamic changes between novice to expert modes (Miraz et al., 2021). In the design of such systems to achieve a good fit to the user needs “*saying the right thing at the right time in the right way*” was essential and required an in-depth understanding of the users (Fischer, 2001). The presented design guidelines in this thesis, would contribute to the design of adaptive systems for lymphoedema self-management. In this study, in-depth insights about the experience of living with lymphoedema was gained, and translated into actionable guidelines for designers, to allow providing the right support at the right time in the right way.

The presented components and stages of the self-management journey, and the guidelines for providing stage-specific support would potentially be valuable also for

lymphoedema professionals. These could inform support provided during face-to-face consultations, and, for the design of future remote consultation solutions. Lymphoedema therapists that participated in this study agreed on the stages PLWL were going through, and explained how they would tailor their support intrinsically depending on the experience of their patients. They explained the influence of the experience of the therapists in being able to adapt the support appropriately. In clinical practice, some lymphoedema professionals were observed to tailor their support strategies depending on the expertise and the needs of their patients, in a similar manner to the proposed guidelines in this study. In nursing theory, adaptation of the provided support according to the changing needs of the patient was an established practice (Katherine Renpenning & Taylor, 2003). However, this was usually conveyed as a professional skill linked to the expertise of the healthcare providers, and how to achieve such an adaptation in lymphoedema was not documented, or explicitly described in the literature. Only Jeffs et al. (2016)'s study described a change in the knowledge needs of PLWL with their increased expertise in self-management. This was not frequently discussed in the literature for the self-management of other chronic conditions either. One study investigated the influence of expertise on the self-management of people living with diabetes (Lippa et al., 2008). Lippa et al. (2008) evidenced that expertise in diverse professional domains such as problem detection, knowledge organisation and problem-solving, affected their performance in health management. In line with the findings of this study, they asserted that self-management interventions should not only be limited to supporting disease specific aspects, but focus on broader skills such as sensitivity to cues and problem-solving (Lippa et al., 2008). Similarly, Nunes et al. (2015) suggested considering patient's "*level of understanding of health data*" while deciding on how to display the data on the chronic condition. In this study, guidelines to support patients at various stages of their self-

management journey in terms of their level of skills, motivation, habits and socio-psychological status are presented. The findings of this study could potentially be valuable for lymphoedema therapists by showing the particular ways to personalise their support in relation to the stage of the patient and to facilitate their empowerment.

Another area that this study could contribute to is remote consultations.

Lymphoedema services had been described as `hands-on` and not well-suited for remote consultation because of the need to have accurate measurements for compression garments, and to assess tissue and change in fluidity (Elwell and Sneddon, 2020). However, during the Covid-19 pandemic of 2020/21, it was not possible to continue many healthcare services face-to-face. Even though, previously face-to-face diagnosis and therapy deemed essential, and there was a reluctance towards teleconsultations, a quick shift to teleconsultation was adopted by many healthcare services during this time (Drouin et al., 2020), including lymphoedema services (Noble-Jones et al., 2021). Guidelines for teleconsultation was published, and these described ways to take measurements at home for patients including the types of measurement tools they should use, how to mark and measure correctly (Noble-Jones et al., 2021). However, patient contact was mostly through telephone calls, with limited access to video calls and lymphoedema professionals found it challenging to assess patients without visual information (Gabe-Walters and Noble-Jones, 2021). Covid-19 necessitated a quick shift to teleconsultation and highlighted some of the limitations of the current technologies used. Wrap-to-Measure and My-Lymphy-Diary used in this study could potentially be valuable for further developments of systems to facilitate conversations between patients and therapists, and help patients to take measurements at home.

In this thesis, the changing needs of PLWL in their empowerment journey, and design guidelines to tailor the provided support according to their stage-specific needs are presented. The rich lived experiences of PLWL and underpinning interdisciplinary theories, are transferred into readily actionable guidelines (Appendix G). These guidelines intend to be valuable for designers who would be developing future self-management support systems, healthcare providers and anyone who is willing to support someone with this chronic condition. The presented guidelines could be implemented for the design of future adaptive self-management support systems, teleconsultation solutions, service design for lymphoedema support and during conversations with PLWL.

7.4 Implications of the Methods for Design Research

In the previous sections, empowerment in lymphoedema self-management and design guidelines for facilitating that journey were discussed. This section discusses the research methods practiced in this thesis and their implications for design research. The first sub-section looks in literature review as a data collection method in design research and the second sub-section discusses the methods and approaches used in this study to design with the `empowered patients`.

7.4.1 Literature Review as a Data Collection Method in Design Research

At the beginning of this PhD study and prior to primary studies with PLWL, a literature review was initiated for building an understanding of the lymphoedema experience. The literature search could not find evidence of studies about lymphoedema experience within design research literature or for design purposes. Yet, lymphoedema experience was explored thoroughly from a health sciences perspective. After starting the

review, the breadth and depth of these studies in describing the experience of living with lymphoedema was perceived invaluable for this thesis. In order to maximize the benefits these secondary studies could have for this study, the review was extended by following a systematic selection method. These qualitative studies conducted with PLWL were thematically synthesised and presented in Chapter 4.

In design research, there is a great emphasis on the use of primary research methods to gain insights from the stakeholders and the intended end-users. Conversely, ways to collate and synthesise interdisciplinary secondary research to design related studies has received limited attention. Even though secondary research is deemed essential for design research, it is rarely perceived and utilised as data collection. The focus in primary research in design is important and legitimate, because of the unique characteristics of design research and types of insights gained through such design approaches. As discussed in Chapter 3 design research is future focused, iterative and collaborative. While literature about lymphoedema in health sciences fundamentally focused on the current experience of study participants, this study investigated their future dreams and how we might design for them. However, in order to make such a jump into the future, a good understanding of the existing experience was required. In health sciences, the current experience of living with lymphoedema was extensively studied, and provided the potential to allow for precious insights for design research. In this thesis, the presented literature review (Chapter 4) created a good understanding of the present lymphoedema experience. The literature review built the foundation for planning the following primary studies with PLWL and their healthcare providers, hence set the scene for exploring the future. This systematic review of the literature also allowed understanding of a wider population than it would be possible to reach otherwise, within

the time limitations of a PhD study. The review included qualitative insights from 495 PLWL in different countries and demographics.

The theories and models on health behaviour and self-management are the other fields in the literature that have had limited influence in the design of healthcare products and services. Previously in the literature, the shortfall in eliciting the dynamic needs of patients and health behaviour theories were discussed to be limiting the effectiveness and use of the products designed for healthcare (Nunes et al., 2015, Riley et al., 2011, Sawesi et al., 2016). Health behaviour is a complex phenomenon and its limited understanding in design could lead to users' early disengagement from the product. There are many established theories and models related to self-management behaviour and psychology (See section 2.3). However, their consideration in the design of support products and systems have been limited. In this study, theories on human behaviour were influential in the synthesis of the voices of people with lymphoedema. This allowed bringing the well-established theories on health behaviour to guide the future design solutions.

One of the learnings gained from this PhD study was the value of collating, synthesising and transferring interdisciplinary literature for design research and design practice. This thesis provided a case where such systematic investigation of the literature promoted the foundation of a model and guidelines for design. The theories on human behaviour are too general to be able to directly apply for design, while the voices of PLWL were specific to their particular context. For the first time in this thesis, these were synthesised and presented in a way that could be implemented for the design of future self-management support systems.

7.4.2 Designing with the `Empowered`: Understanding the Past, Present and Future of Self-Management

In design research, manifestation of `empowerment` has not been limited to the outcomes (design as noun), but has been also about the design process (design as verb). `Empowering` design processes in health and wellbeing, have been characterised as using participatory and collaborative design methods, which encourage the active involvement of people/patients in design (e.g. Winton and Rodgers, 2019, Uzor et al., 2012, Chamberlain and Partridge, 2017, Flinn et al., 2013). In this section, the `empowering` design process followed in this study is discussed. The presented design research process encouraged the active involvement of the participants living with lymphoedema, who were `empowered` in their self-management.

PLWL attending support groups and patient days in lymphoedema conferences were recruited to this study (Chapter 3). There were no inclusion or exclusion criteria about the expertise or empowerment of the participants in their self-management. Still, PLWL who were proactive in seeking support for their self-management, and who had some experience in their self-management participated in the study, because of the followed recruitment approach. Hence, all the study participants were at the empowered stage in at least one of the components of their self-management journey according to the proposed `Model of Empowered Self-management`. Future research should investigate the presented model and the guidelines, with participants that are not empowered in their self-management. Despite its limitations, working with PLWL at the empowered stage proved to be beneficial to investigate the future of design in self-management support. Previous research has identified the challenges in reaching patients as study participants and facilitating their effective involvement in design research studies (Groeneveld et al., 2019).

Working with `empowered patients` provided some advantages in this respect. Empowered patients were easy to get in touch with and were eager to contribute to the design research study. They were proactive in finding solutions and keen to create awareness for lymphoedema by telling their story. They were eager to attend and be involved in interviews and the co-making workshops. `Empowered` stage was also corresponding well with the characteristics of the participants that were previously described to be more effective in design research: `lead users` (Von Hippel, 1986, Pascale et al., 2010). They were the ones achieving good results in self-management despite previous challenges, and so they were problem solvers. Their strategies in overcoming these challenges were invaluable while exploring ways to support PLWL by design.

In this study, regarding the experience of the study participants with lymphoedema, there were three main inquiries (Figure 7-1):

- 1) Past:** looking into what participants `remembered and said` about how their self-management experience was in the past,
- 2) Present:** looking into what participants `did and said` about how their self-management experience was at the time of the study,
- 3) Future:** looking into what participants `made and dreamt` about, to explore how might we design to support PLWL in their empowerment journeys.

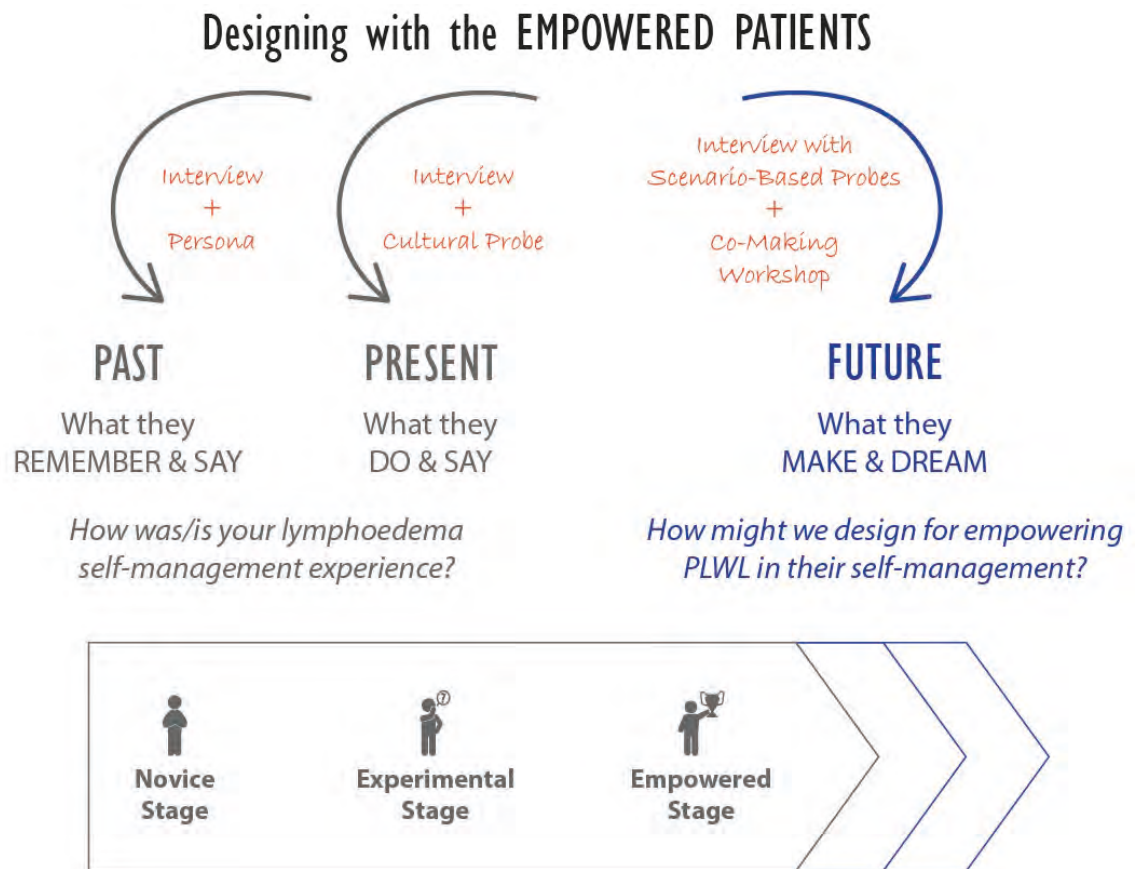


Figure 7-1 Designing with the 'Empowered Patients': Understanding the Past, Present and Future of Self-Management

PAST: During the thematic analysis certain stages were recognised among the empowerment journey of the participants. Yet, these stages were not always a description of how participants depicted their self-management at the time of the study, some of these were reflections on their past experiences with lymphoedema. Prompted by interview questions participants described their self-management journey, though initial responses were mostly limited to the milestones in diagnosis and treatment. The use of personas during the interviews facilitated further conversations about the particular support needs of participants at certain times. Persona used during the interviews was a description of someone recently diagnosed with lymphoedema and at the novice stage of the empowerment journey. Barriers to self-management as described by PLWL in the

literature at this stage was explored with the participants, with the use of the persona (section 5.2.2). This method was particularly effective in sensitising participants about the past and in helping them to remember how their experience was and how their self-management evolved. The persona and the scenario-based probes encouraged participants to talk about and compare their support needs at the time of the study and how it used to be in the past. Persona as a research probe was new to the participants of this study. It was observed to be more effective when the participant was further away from the described novice stage in the persona. That might be because of the fact that participants who are closer to novice stage preferred talking about the challenges they personally encountered. While the ones with increased empowerment were better able to provide advice to the `novice` persona when challenges were described. Persona method was also used during the group interview with the lymphoedema therapists. During this interview, persona method was effective in encouraging comments on the stages of the lymphoedema self-management journey. Persona is a method that is frequently used by designers. Yet, it was not common as a research probe to be used with patients and for the purpose of sensitising participants about their own past experiences. Future work could look into the effectiveness of persona as a research tool to investigate journeys and long-term experiences, and their use in the design of adaptive technologies.

PRESENT: During the interviews, the present self-management experience of the participants were inquired in detail. Even though self-management being second nature to them, some aspects were easy to omit and challenging for them to thoroughly explain. What people `do` and `say` could also differ, especially because of the habitual nature of self-management. Observations are commonly used to complement interviews to gain an understanding of what is `done` besides what the participants `said`. However, in this study the researcher could not conduct observations, because of the private nature of

lymphoedema self-management. Instead, cultural probe method was used aiming to gain insights about what participants `did` on an everyday basis. Further, cultural probe method has the advantage of allowing participants to engage with the probe over time and in their own personal space without the presence of a researcher (section 3.2.5). Participants took the cultural probes to their homes and were encouraged to fill it before, during and after self-management. However, the analysis of the cultural probe proved limited in terms of capturing self-management experience in real-time. Participants used the cultural probe more as a reflective journal and less as a tool to capture what they did in real time. This might be related to the differences in use by novices and empowered patients as discussed in section 7.2, which should be investigated as future research. Still, the cultural probe allowed gaining further insights about the everyday self-management experience.

Moreover, the cultural probe facilitated understanding the real-use of the co-made `Wrap-to-Measure`. Despite, participants commented on perceiving `Wrap-to-Measure` useful and easy-to-use, most of them did not use it during the allocated time for the cultural probe study. Hence, a difference between perceived-usefulness and actual-use of this tool was reported. Cultural probes proved to have potential for capturing the real self-management experience. This could be considered as a research method to gain an understanding of the everyday experience of participants and to test prototypes, particularly for cases where observational studies could not be conducted. Future studies could focus on how to encourage more input from the participants in everyday basis and capture their self-management experience in real-time, besides investigating the difference in their `usage` depending on whether or not the participant is empowered in their self-management.

FUTURE: The main research question and focus of this study was `future`, to explore opportunities to support PLWL better by design. Among the methods described in Chapter 3, scenario based-design probes and co-making workshops were the most effective

ones in exploring how we might design for PLWL to support them in the future. Use cases describing a future self-management support system was communicated with the participants through a scenario. The scenario-based probes encouraged participants to talk about their goals, needs and possible future experiences, instead of specific technologies or design decisions. Talking about future use-cases before the development of any prototypes allowed gaining insights about the very early design decisions and without the constraints of participants' perception of the related technologies. This also created flexibility for participants to manipulate the scenarios and depict their own ideal future. Scenario-based probes helped to set participants at their ease and think about what could have been helpful for the self-management without the constraints of the systems or technologies that they know of. The probes were valuable to make participants feel comfortable in sharing ideas that they might have perceived unrealistic and so not worth mentioning otherwise. The persona as an actor in the scenario allowed participants' engagement with the activity as co-designers and highlighted differences in the goals of the participant and the persona as a reflection of themselves when they were diagnosed. Using scenarios instead of prototypes also posed limitations, because of the potential difference between perceived-usefulness and actual-usage. The co-making workshop and cultural probe study allowed gaining some insights about the actual-use behaviour of the participants, though this did not allow testing all the presented design guidelines. Future research should look into testing and comparing the actual-usage of an adaptive support system by individuals at different stages of their self-management journey. The other method that was utilised for gaining insights about 'future' was the co-making workshop. During the co-making workshops, participants were encouraged to make a 'Wrap-to-Measure' tailored for their own dimensions and needs. The 'making' activity required close attention to lymphoedema and collaboration with others during. Participants took their Wrap-to-Measures home and were encouraged to use

it with their My-Lymphy-Diaries as a part of the cultural probe study. The ways participants engaged with the activity provided deeper insights about their approaches and goals for self-monitoring, while the cultural probe tested their actual use for a period of two months.

In this study, designing with `Empowered Patients` allowed not only to explore the present self-management experience of the participants, but also their `past` and desires for `future`. Designing with `empowered patients` as study participants, and `design probes` as research methods were effective in exploring the needs of PLWL.

This study prioritised the `empowerment` and active involvement of the study participants with lymphoedema through the use of design probes. The empowerment journey of PLWL and design guidelines to facilitate this journey are presented as a result. Self-Management support systems for PLWL should be designed to adapt to the changing needs of the users while they gain empowerment in their self-management. Design guidelines were provided to allow the delivery of the right support for the individuals at the right time for them and in the right way. Conclusions are presented in the next chapter.

Chapter 8 Conclusion

This thesis investigated ways to support the empowerment of PLWL in their self-management. This was achieved by following an iterative, collaborative, and empowering design research approach. First, a literature review of systematically selected studies on lymphoedema experience was conducted (Chapter 4). These voices of PLWL were synthesised from the perspective of established theoretical models related to self-management. These included theories on human behaviour, motivation, adaptation, learning, sociology, and psychology. This synthesis was followed by observations and informal interviews in lymphoedema clinics (Section 5.1). Then, one-to-one interviews with PLWL were conducted utilising scenario-based probes (Section 5.3). That led to the development of a cultural probe (Section 6.1). This cultural probe was introduced to the study participants with lymphoedema during a co-making workshop (Section 6.2). The results of these studies were discussed with lymphoedema professionals during a group interview (Section 6.4).

As a result of this PhD study, a new and dynamic model of empowerment in self-management is presented. Patient empowerment has been set as a goal for self-management in healthcare organisations. However, the meaning of empowerment according to the patients themselves was lacking, and there was no guidance on how to design supportive systems and products for patient empowerment. Previously in design context, experience of a chronic condition has been widely considered as a static behaviour-change quest. The design would be assessed as a single product or system in terms of its fit to the user needs. However, this approach underestimates the evolving needs of patients that depend on their growing expertise and progression towards empowerment

in their self-management. Moreover, previously, focus on design was mostly about provision of information and behaviour change for self-management, whereas the socio-psychological aspects of the everyday experience of living with a chronic condition and the possible adaptations to self-management regimes were overlooked in design. This study presents the stages of the empowerment journey and the multidimensional support needs of the individuals at these stages. This facilitates understanding the stage of the user and tailoring the design of the provided support accordingly in a comprehensive manner. The user at these three stages had different needs, and therefore, proposed support should be treated as three separate designs. In this thesis, actionable guidelines for addressing these stage-specific needs of PLWL are presented. The previously abstract empowerment concept has been operationalised, and a platform for design for empowerment is proposed. While this thesis is specifically focused on lymphoedema, potential implications and directions for future research for other chronic conditions and life changing events are identified and discussed. The outputs of this thesis can be useful for designers to facilitate the personalisation of healthcare products and services; for training of healthcare professionals to support the empowerment of their patients, and for policymakers in healthcare to provide an empowerment focused approach to self-management. The presented guidelines (Appendix G) aim to facilitate patient empowerment, by providing the right support at the right time and in the right way. Everybody wants to take care of themselves, but the ways they should be supported to achieve this is different depending on where they are at in their self-management journeys.

In this thesis, the following main contributions to knowledge were made:

- **Empowerment in self-management:** The meaning of empowerment for PLWL is presented in Table 7-1 and explained below:

Empowerment is the multifaceted journey of the patient that extends well beyond `increased power in decision making`. Empowerment is the gradual acquisition of competence (feeling physically and intellectually capable to self-manage), autonomy (feeling motivated, responsible of and in-control of self-management), habit (balanced adaptations that makes self-management a part of everyday life), psychology (coming to terms with living with the condition), identity (adaptations to changing roles/identities with the condition) and support network (feeling well-supported and connected).

- **The Model for Empowered Self-Management:** In this thesis, a unique stage-based approach to empowerment in self-management is presented. The Model for Empowered Self-Management demonstrates the components and the three stages the PLWL went through towards empowerment. It is shown that PLWL's support needs were evolving and were different at these stages (Table 5-6).
- **Design for Empowerment Guidelines:** Self-management support systems should be designed to adapt to the changing needs of their users while they progress towards empowerment. In this thesis, design guidelines for addressing these stage-specific needs of PLWL are provided. Such stage-based personalisation is needed to be able to facilitate the empowerment of people in their self-management, since accessing the right support at the right time was key. These guidelines are presented in a way that can be implemented by the healthcare professionals and the designers of future self-management support systems and products (see Appendix G).

In addition to the above, the followed design research process with empowered patients presented the following contributions to the knowledge: This study presents a design research approach for and with people living chronic conditions. Designing with `empowered patients` as study participants was shown to be effective. These empowered patients were proactive problem solvers and were keen to be involved in research studies to increase awareness on the issues related to their condition. `Design probes` including scenario-based and cultural probes were effective in investigating the needs of people living with chronic conditions. These design probes allowed to investigate the past and present self-management journeys of empowered patients, besides exploring with them `how the future might or should be`. Design research grounded this future-oriented investigation by abductive reasoning and in collaboration with PLWL, and so tackling this subject matter through design research was important and provided valuable contributions.

LIMITATIONS AND FUTURE RESEARCH:

All research projects have limitations due to the choices that must be made in consideration of time constraints, approaches in methodologies and participant selections. The key limitations in this study are presented below, together with new research questions that might address such limitations:

- **How might the severity of lymphoedema influence the self-management journey towards empowerment?** The severity of lymphoedema was not a recruitment criteria for this study. This was due to not having a large pool of participants with lymphoedema, and so not to constrain recruitment. All participants of this study had mild-to-moderate lymphoedema, and none had severe symptoms. The influence of severity of the chronic condition on the self-management journey was acknowledged in

this study. However, it was not possible to investigate how severity influenced the empowerment of PLWL. Future research should investigate the difference the severity of the condition makes in people's self-management journey, and how design might vary depending on these differences.

- **How might the `Design for Empowerment Guidelines` be utilised by designers in the development of an adaptive self-management support system?** Guidelines for providing support that matches the stage specific needs of PLWL are provided.

However, the effectiveness of these guidelines in product development process is yet to be evaluated by designers. Future work should focus on the assessment and implementation of these guidelines in the development of adaptive self-management support systems. One potential research direction could be to test the implementation of the model and guidelines with product design students. The other potential is to work in collaboration with industry partners for the development of an adaptive self-management support system. Moreover, the `Design for Empowerment Guidelines` (Appendix G) can be transferred into and disseminated as a digital tool, to understand the stage of the patient and suggest stage-appropriate support strategies. This could potentially be useful for designers and healthcare providers while adapting the support they provide to PLWL for facilitating patient empowerment.

- **How might the `Model for Empowered Self-Management` be utilised for developing a training programme for healthcare professionals?** Healthcare professionals described that tailoring the support according to the level of their patients, was an implied skill that was developed by growing expertise as a professional, and that was not always achieved by the ones that were new to their roles. Hence, there is potential value in utilising the model for empowered self-management

to develop guidelines and training programmes for healthcare providers. That could potentially raise more knowledge and awareness of the holistic and gradual support needed for facilitating empowerment. Future work should focus on understanding the gaps in the professional training programmes regarding patient empowerment and developing/refining the model to provide guidelines specifically for healthcare professionals.

- **How might we design systems to support teleconsultation of lymphoedema?** The focus of this study was the self-management of the individual with lymphoedema. Remote professional management by lymphoedema therapists started to gain more attention during the Covid-19 pandemic. Teleconsultation demanded more decision-making from the patients, and therefore, they were expected to gain a higher degree of empowerment in a shorter period of time. As future work, the teleconsultation experience in lymphoedema management can be investigated to present design solutions that match the needs of both patients and their healthcare providers. The `Design for Empowerment Guidelines` could potentially be implemented in this context of chronic condition support.
- **How might the usage of self-management support systems differ depending on which stage the users are in their journey towards empowerment (i.e., novice, experimental, empowered)?** All the participants of this study were at the `empowered stage` in at least one of the components of the self-management journey. At the start of this research as well as during participant recruitment, the stages towards empowerment had not been defined yet. Hence, the level of empowerment was not a recruitment criteria. Nevertheless, as a natural result of the approach followed here (information sheets were distributed to patient support groups), the PLWL who

participated in the study were closer to the Empowered Stage. Working with Empowered Patients had some advantages, as participants were able to report on their process towards empowerment and their experience in these stages. However, this also brought some limitations to the study. The actual-use behaviour of individuals at novice and experimental stages have not been inquired yet. In reference to the literature, it can be hypothesised that novice and empowered users could be using a support system for different purposes and in different ways. Future work should investigate the usage of a support system by participants that are in the novice, experimental and empowered stages.

- **How might we facilitate collaboration with `empowered patients` in design?** This study presented some opportunities in collaborating with `empowered patients` in design research. This was facilitated by scenario-based probes, cultural probes and a co-making workshop in this study. There is an opportunity to investigate the methods and approaches to facilitate collaborations with `empowered patients` further.
- **How might the Model for Empowered Self-management be applied to other chronic conditions and beyond?** The presented model is developed specifically for lymphoedema. Still, similarities with other models suggest potential for applicability for other chronic conditions. A broader study could investigate the components and stages of empowerment across chronic conditions (diabetes, hypertension, asthma, cancer etc.) and identify generalisable aspects, as well as specifics of these conditions. Such future work could potentially allow development of a model that is applicable for self-management in other chronic conditions and in broader contexts for other circumstances that require transitions, challenging life journey and big changes in people's lives.

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Appendices

Appendix A – List of the Systematically Selected 31 Articles on Lymphoedema Experience

	SOURCE	N	INCLUSION CRITERIA	METHOD OF DATA COLLECTION	STUDY OBJECTIVES	ORIGIN
1	(Barlow et al., 2014b)	14 women	BCRL / upper limb	In-depth semi-structured at homes (n=14) / focus groups interviews (n=15)	Participants “views of their care and treatment”	UK
2	(Bogan et al., 2007)	3 men, 4 women	Non-cancer related primary / lower limb / advanced lymphoedema	Semi-structured interviews (qualitative description)	Experience of “advanced and complicated cases of lymphedema” (treated in an inpatient setting)	USA
3	(Cal and Bahar, 2016)	14 women	BCRL / upper limb	In-depth semi-structured interviews. Inductive content analysis	“Barriers to prevention of BCRL and home care needs”	Turkey
4	(Deng and Murphy, 2016)	13 men, 7 women	Head and neck lymphoedema (HNL) patients	Semi-structured interviews, Qualitative description	“Perceived lymphedema education, self-care practices, and suggestion.”	USA
5 (4)	(Deng et al., 2016)				“Emphasis on physical findings and associated symptom burden”	
6	(Fu, 2008)	22 women	BCRL / upper limb	A descriptive phenomenological method. In-depth interviews	Experience of work of people with BCRL	USA
7	(Fu, 2010)	34 women	BCRL / upper limb	In-depth interviews (descriptive phenomenological)	Compare the perception of compliance of BCRL and their clinicians	USA
8 (7)	(Fu and Rosedale, 2009)			Three groups: White, African American, and Chinese American	BCRL symptom experience	

10	(Heppner et al., 2009)	10 women	BCRL / upper limb	In-depth interviews. Consensual qualitative research.	"Stressors associated with lymphedema, how women cope with the stressors, and the role of social support"	USA
11	(Honnor, 2009)	16 women	BCRL / upper limb	Semi-structured interviews	Information needs of BCRL	UK
12	(Jeffs et al., 2016)	21 women	BCRL / upper limb / mild-moderate in severity	In-depth interviews	Perception of success and benefit of BCRL self-management	UK
13	(Karlsson et al., 2015)	16 women	BCRL / upper limb	Semi structured interviews. Phenomenographic	Perceptions of lymphoedema treatment of BCRL	Sweden
14	(Lindquist et al., 2015)	8 women	BCRL /	Open interviews / phenomenographical	Experience of BCRL	Sweden
15	(Maree and Beckmann, 2016)	8 women 1 men	BCRL / upper limb	Unstructured interviews	Experience of BCRL	South Africa
16	(Maxeiner et al., 2009)	1 male primary, 1 female secondary, 1 male secondary	Primary and Secondary	semi-structured interviews with 3 people and survey with 47	Comparison of psychosocial issues with primary and secondary lymphedema	USA
17	(McGarvey et al., 2014)	10 patients, 10 health professional	Head and neck lymphoedema (HNL) patients	Semi structured one-to-one interviews	The effect of HNL, beliefs of health professionals about the risks, how HCL might be effectively managed	Australia
18	(McGrath, 2013)	7 women	BCRL	Three rounds of in-depth semi-structured interviews over a three-year interval	Experience of BCRL from occupational therapy	UK, Ireland
19	(Meiklejohn et al., 2013)	3 men, 26 women	Secondary L. After cancer treatment / upper or lower limb	Focus group and semi-structured interviews	Experience of lymphoedema "following treatment for any cancer in the context of everyday life"	Australia

20 (21)	(Armer et al., 2009)	14 women newly-diagnosed BCRL	BCRL / upper limb / prevention	Questionnaire, phone interviews and hand-written return surveys. /Orem's description of the power components.	"To enhance a supportive-educative nursing system for breast cancer survivors to reduce the risk of developing lymphedema"	USA
21	(Radina et al., 2014)			Feminist family theory-informed secondary analysis/ secondary analysis of data generated in 20	BCRL risk reduction "within the contexts of complex and demanding social responsibilities that may elicit gendered self-sacrificing behaviors."	USA
22	(Ridner et al., 2016)	21 women	BCRL / upper limb	Focus group interviews	BCRL experience and the support needs that are perceived critical	USA
23	(Ridner et al., 2012)	39 women	BCRL / upper limb	Writings at home for two weeks (descriptive qualitative)	Perceptions and feelings related BCRL	USA
24	(Thomas and Hamilton, 2014)	11 women, 2 men	Cancer related Lymphoedema	Semi structured interview. Phenomenological Interpretive description	Physical and psychosocial aspects of secondary lymphedema after cancer	Canada
9 (24)	(Hamilton and Thomas, 2016)			interpretive description design	"Hope and what made them hopeful, against the backdrop of developing a chronic condition"	
25	(Towers et al., 2008)	11 patients, 8 spouses	Cancer related Lymphoedema	Semi-structured interviews	"Experience of patients with cancer-related lymphedema, and their spouses"	Canada
26	(Tsuchiya et al., 2012)	10 women	BCRL / upper limb	Focus group discussions. Inductive thematic analysis.	"How the provision of medical information by doctors affected the problem-solving processes of Japanese" BCRL	Japan (same study different analysis)
27 (26)	(Tsuchiya et al., 2015)		BCRL / upper limb	Focus group discussions. Thematic analysis and conceptual analysis,	Japanese BCRL patients' "decision making about disclosure of lymphoedema symptoms to people in their social networks."	
28	(Viehoff et al., 2015)	31 people	Primary and secondary	Six different focus groups were used,	"Identify and quantify meaningful concepts in lymphedema from the	Netherlands

			lymphoedema	each with 3–8 participants.	patients' perspectives using the International Classification of Functioning, Disability and Health (ICF)"	
29	(Wanchai et al., 2012)	29 (18 women USA, 11 South Africa)	BCRL / upper limb	Ethno-nursing research method, semi structured interviews	Compare experiences and lymphoedema managements between BCRL from USA and South Africa	USA and South Africa
30	(Watts and Davies, 2016)	49 women, 10 men	Primary and secondary lymphoedema	8 focus groups in every Welsh Lymphoedema Clinic. Qualitative content analysis	"People's experiences of living with lymphoedema and "impact of access to local lymphoedema clinics on their condition"	UK, Wales
31	(Rhoten et al., 2016)	18 women	BCRL / upper limb	Focus group interviews	Body image in BCRL	USA

Appendix B – Participant Information Sheet and Consent form

Participant Information Sheet

TITLE OF PROJECT: Lymphoedema Self-management / Interview

NAME OF RESEARCHER: Teksin Kopanoglu

You're invited to take part in this research, because your experience will help us better understand lymphoedema self-management. This research is a part of my PhD. Your personal information will not be shared with anyone else. Your responses to the questions will be used for the purpose of this project only and as anonymised quotes in research publications. Joining the study is entirely up to you. Before you decide, I would like you to understand why the research is being undertaken and what it would involve for you. I will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any questions you may have. Please feel free to talk to others about the study if you wish.

The Participant Information Sheet tells you the purpose of the study and what you would do if you take part.

Please ask if anything is unclear.

WHAT IS THE RESEARCH ABOUT

I'd like to talk to you to understand your lymphoedema self-management experience. I want to understand how was it for you when you were first diagnosed with lymphoedema, how is it right now and how it might be better supported in the future. There are no right or wrong answers. We believe this understanding can help us in developing self-management support systems for people with lymphoedema. This study is a part of wider research, to guide us in facilitating design workshops with people with lymphoedema and their healthcare providers.

YOUR PARTICIPATION IN THE RESEARCH

What would happen if you agree to join the study?

On the day of the study, I will go through the information sheet with you and answer any questions you have. If you agree to take part, I will then ask you to sign the consent form. You are free to withdraw at any time, without giving a reason.

I will give you a one page questionnaire, which is optional and only for monitoring participant demographics. I will then invite you to talk about your lymphoedema experience. There will also be some visual aids.

How long will it be?

Session will be roughly 1 hour

Where will it be?

You're very welcome to come to our university campus at Llandaff, Cardiff. We can also provide parking free of charge at the campus area.

Address: PDR,
Cardiff Metropolitan University
Western Avenue
Cardiff
CF5 2YB

Please note: The PDR building is located on the far right of the university campus when you are facing the main Campus reception.

If this location isn't suitable for you, for any reason, I can carry out the interview where you prefer. Please mention your preference.

Are there any risks?

There are no identified risks associated with this study. If, at any time, you feel like you do not want to continue with the session, you may withdraw without giving any reasons.

Are there any benefits from taking part?

There are no immediate benefits for participating in the project. The knowledge gained from this study will help us to better understand lymphedema self-management. In the long term, we hope this study will help us in developing products that support and improve the self-management experience of people with lymphoedema.

How do we protect your privacy?

I will be audio recording and taking notes during our conversations. All the information about you, including the optional questionnaire, will be stored separately to your name and consent form, so that you are not identifiable through your responses. Your responses to the questions will be used for the purpose of this project only and as anonymised quotes in research publications.

The personal information I have gathered about you will be deleted once the PhD is completed. Your email address may be kept if you give consent to be contacted for future studies, which is optional in the consent form. Video recording is optional.

No one outside the project will be allowed access to your name, e-mail address and recordings.

What happens next?

If you are happy to take part, please contact me. I will email you a consent form so you can review the documents and on the day of the session you will be asked to sign them.

WHO ARE PDR

PDR is a design and innovation consultancy and research centre. We are part of Cardiff Metropolitan University and all studies are approved by ethics boards. If you would like to find out more about PDR, please visit our website: www.pdronline.co.uk

FURTHER INFORMATION

If you have any questions about the research or how I intend to conduct it, please contact me:

TEKSIN KOPANOGLU

RESEARCHER

TEL: +44 (0) 29 2041 6073

EMAIL: tekopanoglu@pdronline.co.uk

Consent Form

PARTICIPANT NAME:

TITLE OF PROJECT: Lymphoedema Self-management / Interview

NAME OF RESEARCHER: Teksin Kopanoglu

PARTICIPANT TO COMPLETE

Please initial the boxes to indicate your agreement with the following statements -

Statement	Initial
1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason	
3. I agree to notes to be taken and being audio recorded during the study	
4. I agree to the use of anonymised quotes in research publications	
5. I agree to take part in the above study	
Optional:	
6. I agree to being video recorded during the study	
7. I agree for you to contact me for research follow up or to know about other research opportunities. My email address is:	

Please sign and date:

Signature: _____ Date: _____

RESEARCHER TAKING CONSENT TO COMPLETE

Signature: _____ Date: _____

Appendix C – Supporting Material for Chapter 4

C1. Competence: Stages and Key Quotes from the synthesised articles

Stages	Key quotes of PLWL from the synthesised articles
Novice `I have some knowledge about self-management`	<p>"I'm not a dunce but I just find it very difficult to follow a sheet [instructions]. I'm more practical. I prefer someone to show me, and she has shown me but only once and I can't, I didn't take it in. (...) I'm going to have to be shown again but it's me having to ask her really, and she's so busy." (Jefferis et al., 2016)</p> <p>"Yeah we talked a lot about it. Um they tried to educate me. I am a visual learner though, unfortunately, so we did not see the actual pictures of it which would have helped me. But they, they explained it and I took in as much as I could." "She (lymphedema therapist) showed me... Oh yeah (she was a good teacher). I am just not a good student." (Deng & Murphy, 2016)</p> <p>"I have gotten different answers from different people regarding activity with the affected arm. My general surgeon says to treat it completely normal, lift whatever I want, do whatever I want, etc. The lymphedema therapist of course says otherwise." (Ridner et al., 2012)</p>
Proficient `I have knowledge, skill and experience about self-management`	<p>"Partly at work, when I am sitting in front of the computer: I go out for a while. Now I have to go to the printer and that is good. Print instead of saving a few jobs as I used to do earlier, now I go out for each, so I get to take short walks continuously. And I think about not carrying out repeated movements too long, but take breaks. And I feel that this is something that makes me feel good. both helping the lymphedema and in helping my psychological well-being" (Lindquist et al., 2015)</p> <p>"Alright, putting on the sleeve I must admit you do have to wrestle and I imagine for an older person, they would need help. But now I've got technique, and I've learned to get a little a cushion and put it by the side [of my face] and hold and pull up [the sleeve] so that I don't punch myself in the face (laughs)." (Jefferis et al., 2016)</p> <p>"...[lymphoedema therapist] basically showed me. Had a picture and showed me what had been removed in my neck and the numbers. And how the lymph system works, and why the swelling was coming, and why it was so much in that forward area based on where I'd had the surgery. Yep, he explained the mechanic(s) of how it works and then how to express to try and help release the fluids into the other pathways that are open. He said that by doing this, too, you would create new pathways that would probably start to handle it naturally on its own." (J. Deng & Murphy, 2016)</p>
Expert `I have experience in managing fluctuations and in a variety of situations. I can intuitively give self-management decisions.`	<p>"Whether you are in the hospital making sure—you know, sleeping with one eye open making sure they don't stick you, whether you're preparing yourself for a flight by wrapping your arm, whether you're thinking ahead of, 'Do I have my antibiotics with me today? I'm going to be away on vacation. Do I have my back-up antibiotics?' You have to pre-plan. It's not spontaneous that you just run out the door or you could run into some trouble."....I'll take, um, like, a prescription of 10 painkillers and I take all kinds of things with me so that if I get to a place and I'm in a bad situation, I'll have whatever medicines I need." (Ridner et al., 2016)</p> <p>"It's like most people with lymphoedema become experts because you go on the internet, because GPs know nothing... Even now, so you make sure that you're an expert..." (Barlow et al., 2014)</p> <p>"...I feel, I can handle it. I'm careless sometimes, but then I know how to get on the right path again... The treatment for lymphoedema is described as a process in which patients need to figure out which parts of the treatment give them the desired effect." (Karlsson et al., 2015)</p>

C2. Autonomy: Stages and Key Quotes from the synthesised articles

Stages	Key quotes of PLWL from the synthesised articles
Amotivated `I can't manage` `I don't have a role in managing`	<p>"Lymphoedema seemed to be something like an incoming tide; ... there didn't seem to be anything you could do about it." (Meiklejohn et al., 2013)</p> <p>"Well, to feel like, I'm being treated, someone is taking care of me, and I think it feels safe and secure." (Karlsson et al., 2015)</p> <p>"Participants reported low energy, fatigue, and lack of motivation as some of the reasons for not performing self-care measures." (Armer et al., 2009)</p>
Extrinsic `I feel guilty if I don't` `I was told to do these` `I'm afraid of the consequences`	<p>"Ann described her lymphoedema as an inconvenience, more of a hindrance than breast cancer and the related self-care as a nuisance. She tried yoga and was forced to give it up because of the significant pain that she experienced. Ann reported reluctant compliance with her lymphoedema conservative treatments and regret that she was forced to designate household management tasks: It was only the frustration of not being able to move the arm so I couldn't do what I wanted" (McGrath, 2013)</p> <p>"It doesn't take a rocket scientist to figure out...if I can't control my leg, somebody else is going to control it. And they're going to take it off.", "I don't want to do anything to jeopardize and send my leg going backwards....If I don't do it, I'll be right back up to [the inpatient program] or I'll be over in a hospital somewhere with somebody amputating my legs." (Bogan et al., 2007)</p> <p>"After my arm got swollen, I feared that it (lymphedema) would worsen and that it would be more difficult to do all things" (Cal and Bahar, 2016)</p>
Integrated `Correlates with my goals` `It is a part of my life` `I'm in control`	<p>"I've made myself realise that I've got a choice: I either wear it [the sleeve] and my arm will hopefully gradually go down even more, or I don't wear it and I end up not being able to do anything or I've damaged my arm because I get cellulitis [infection]." (Jefferis et al., 2016)</p> <p>"This is not an issue about whether or not I have listened to my therapist, but how can I best make this work." (Fu, 2010)</p> <p>"I think it is very important because if I become lax and not do it I can tell the difference. I tell the difference in the heaviness of my arm. I try to take care of myself in a way so I don't have to deal with the heaviness." (Radina et al., 2014)</p>

C3. Habit: Stages and Key Quotes from the synthesised articles

Stages	Key quotes of PLWL from the synthesised articles
Intention `I'm considering it.` `I'm not sure if I can manage this.`	<p>"Control over lymphoedema was challenged due to difficulties in remaining physically active or performing lymphoedema treatment and management strategies. A man said, 'I can't exercise too much on my right arm because it becomes too tired; I have a set of exercises I can do ... I don't do those probably as much as I should' (Meiklejohn et al., 2013)</p> <p>"Women reported lack of routine as an influential reason why regular self-management was not done. 'Well, basically, I don't have a routine. It's just very on the moment. I suppose the answer would be a routine and it wouldn't be difficult, like cleaning your teeth, to do the massage if I could get that into my schedule'" (Jefferis et al., 2016)</p>

	<p>My work [gets in the way of my practice of self-care measures]. I'm a lazy person when it comes to taking better care of my body. Between the office and keeping up with housework, I don't seem to have enough time. Seems like my priorities are out of whack, doesn't it? I lack the self-discipline to place my health first in my life. I was taught from a very early age that work is most important and I guess that lesson stuck. I need a way to rearrange my life (Radina et al., 2014)</p>
<p>Adhesion</p> <p>`I do what I was told.`</p> <p>`I'm not sure how to manage fluctuations.`</p>	<p>"I would say my treatment, what I was doing, was quite intense because I was almost fanatical about it. you tend to think it runs your life (...) it was getting in the way at first, you know, I was quite uptight about it at first. (...) [now] I've got mine under control so well that if I wear the sleeve all day busying about the house or whatever then when it comes to my turn to enjoy myself the sleeve comes off, just for a couple of hours or overnight." "Much of life was lived in the middle of these two extremes. At times, treatment was abandoned or carried out obsessively to the point that lymphoedema self-management dictated other aspects of life and family activities." (Jefferis et al., 2016)</p> <p>"I mean, I was anxious to get rid of the swelling. I would have jumped off a roof if he told me to. If I thought that was going to make me get, loose that puffiness in my face and neck." (Deng et al., 2016)</p> <p>"I do what I am told. But the act that it is with your life is a bit of a hindrance" (McGrath, 2013)</p>
<p>Experiential</p> <p>`I try them out`</p> <p>`I'm not sure how to manage fluctuations.`</p>	<p>"Some believed further improvement with self-management activities was unlikely and used trial and error to determine the minimum effort required to maintain an acceptable level of swelling. 'I would say I wear it [the sleeve] 80% of the time, and I think I'm pretty good at doing that. Because I know what will happen if I don't wear it. I leave it off if I'm going out or for whatever reason, but I wouldn't leave it off if I was lifting, if I was doing anything that involved putting pressure on it.'" (Jefferis et al., 2016)</p> <p>"Even though my arm always feels heavy, I don't need to wear compression sleeves. I do massage in the morning... Instead of sleeves, I do massage by myself, using aromatic oil... [I tried to wear compression sleeves]. But once I wore a sport type elbow support, I came to prefer it." (Tsuchiya et al., 2012)</p> <p>"The women in the study listened to their healthcare providers' instructions, however, they did not follow them exactly. Instead, the women tried to 'make lymphoedema care feasible'. For example, the women were usually told to use daily compression. However, barriers such as insufficient time and financial resources, fatigue, fear of losing employment, stigma, embarrassment or discrimination often prevented them from following this instruction. This could be regarded as non-compliant, however, as one of the respondents, Ms Wong, remarked: 'This is not an issue about whether or not I have listened to my therapist, but how can I best make this work.'" "For the women, managing lymphoedema was more complicated than simply complying with the treatment or prescribed daily regimen. Instead of passively following healthcare professionals' instructions, the women actively and creatively structured their lives to 'make lymphoedema care feasible'. The women did not consider selectively carrying out the prescribed daily regimen as non-compliance, but rather as a way of using strategies to 'make daily care feasible.'" (Fu, 2010)</p>
<p>Balanced</p> <p>`I manage my condition despite fluctuations.`</p>	<p>"They adapted their self-management programmes to suit personal goals and symptoms, compromising between the amount of self-management performed and severity of remaining swelling." "In fact, achieving routine was seen by many as key to learning to live with lymphoedema and regaining a 'normal' life." "Some women described reaching a point where lymphoedema was an integral part of who they were, with self-management so much part of normal daily routine that it was no longer consciously planned. 'I just try and live as normal as possible, but obviously it's like restrictions. It's not going to run my life. It's not going to be one of those things you say I can't do that because I've got lymphoedema ... It's [the sleeve's] part of my everyday life now. It's just there and you just do it.'" (Jefferis et al., 2016)</p>

`I have a normal life despite my condition.`

"About the ongoing maintenance phase of self-management, a participant shared, `You kind of felt you were getting back to normal...as normal as you can get and still aware of what you had to do.`...Another stated, `If you can keep it managed, you can live a pretty well normal life.`"(Bogan et al., 2007)

"The fact that managing it seems to be working and it's not really impacting my life to any serious degree" (Hamilton and Thomas, 2016)

C4. Psychological: Stages and Key Quotes from the synthesised articles

Stages	Key quotes of PLWL from the synthesised articles
<p>Overwhelmed</p> <p>`I'm sad and angry about my condition`</p>	<p>"I really do believe the quality of my life has changed and much of it cannot be returned. It makes me very sad. I was really angry about it at first, now I am just sad... How have I felt about the lymphedema diagnosis? Frustrated, angry, sad, and perplexed." (Ridner et al., 2012)</p> <p>"Most participants reported initially denying or avoiding accepting a lymphoedema diagnosis, and some struggled to progress past this point. A woman said, `I kept thinking somebody's going to re-diagnose me and I haven't really got lymphoedema`" (Meiklejohn et al., 2013)</p> <p>"She (College and Association of Registered Nurses of Alberta) gave me a video about exercise for people with lymphedema or breast cancer, and I hated watching it. It took me a long time to watch it. When I did watch it, I started crying because I don't want to be- I just want it to be over." (Wanchai et al., 2012)</p>
<p><i>After cancer</i></p> <p>`Lymphoedema is worse than cancer`</p> <p>`Lymphoedema reminds cancer`</p>	<p>"The first realisation that it was going to be permanent, just emotionally I just didn't want to go anywhere, didn't want to do anything and I felt as though the person that I was before the breast cancer was gone..." (Barlow et al., 2014a)</p> <p>"The physical discomfort from ongoing swelling and other symptoms triggered fears and apprehensions in the women about cancer recurrence, which made some feel "scared" and others concerned that they were becoming some `hypochondriacal.` Mrs. Marnie, a 53-year old white woman who had lymphedema for three years, described her recurring fear: `Whenever I take a look at my ugly arm, it's just like a giant bomb to me. I am thinking, someday, it will bring my cancer back. The mere thought of that scares me.` ...</p> <p>"Lymphedema will never go away. It's a constant reminder of breast cancer. So, you cannot really forget that you had cancer because you are reminded every day." (Fu and Rosedale, 2009)</p> <p>"What bothered me was that I realized it was bothering [my wife] almost more than the cancer itself. I don't know why, but for some reason it indicated to her ... it was a constant reminder to her that she was sick and also, I think. the fact that she knew she had to live with it for the rest of her life was disturbing ... I think she very seldom thinks about having had cancer ... but the Lymphedema is a problem. I mean,, she tugs at her arm constantly and she's constantly aware of it." (Towers et al., 2008)</p>
<p>Reconsidering:</p> <p>`I know my condition is permanent, but I still get upset`</p>	<p>"The fact that I now have to live with so many restrictions on how I do my daily routine is something I have not come to terms with." (Ridner et al., 2012)</p> <p>"` Sometimes I feel I can beat this, other times I feel like giving up on life. This has been the hardest thing I have ever gone through in my life.`" (Maxeiner, Saga, Downer, & Arthur, 2009)</p> <p>"Initially, overwhelmed by all that was entailed in learning to manage lymphoedema, the women found different ways of coping with their changing life, swinging from hope</p>

when symptoms occur`	the swelling would completely resolve to despair that life would never again be normal." (Jeffer et al., 2016)
Coming to Terms with: `I accept my condition and am positive about it. I get on with my life as normal as possible`	<p>"I am living with this condition everyday but not as an invalid but as a survivor. God spared my life and lymphedema was part of the package. That's OK when you consider the alternative."(Ridner et al., 2012)</p> <p>"One individual with secondary lymphedema explained feelings of acceptance by stating, `I am just happy to be alive and have a good prognosis for the future.`" (Maxeiner et al., 2009)</p> <p>"I just think, well, this is a problem but it's going to improve.` She went on to share the quote that she finds very meaningful, `You can't control the waves, but you can learn how to surf.`" (Maxeiner et al., 2009)</p>

C5. Identity: Stages and Key Quotes from the synthesised articles

	Key quotes of PLWL from the synthesised articles
Disruption: `I'm not normal anymore`	<p>"Some participants shared stories about challenges to their roles as caregivers, which in turn, altered their sense of self through a change in role identification. For example, many spoke about difficulties in performing simple nurturing acts, such as simple household chores, cuddling, or carrying or holding hands with a small child or grandchild. Participant comments included "they want to sit on your lap and have a cuddle, that can be really difficult because, they don't understand" (female, ULL, 44 years); "pegging out clothes or doing the washing ... I might do it in three goes instead of one go" (male, ULL, 56 years); "I can't vacuum the house" (Meiklejohn et al., 2013)</p> <p>"The fear of stigma and embarrassment sometimes forced them to forgo the compression garments altogether: `I usually do not wear my sleeve and glove when I am around my daughters and their friends. I am afraid that they would feel ashamed or embarrassed. So, I have developed a strategy to camouflage my [swollen] arm by sitting with it behind my body.`" (Fu, 2010)</p> <p>"He (doctor) says not to lift over 5 lbs., no vacuuming, no repetitive motions, otherwise baby it. I do not like the idea of having to always be aware of what I might be doing to my arm. I want to do things normally." (Ridner et al., 2012)</p>
Re-thinking: `I'm looking for ways to hide my condition, even if that limits me`	<p>"Being able to wear real clothes again was the main motivation. Who wants to wear sweats forever? By being able to wear regular clothes, people don't see the big legs." (Bogan et al., 2007)</p> <p>"I am truly blessed to be able to somewhat go on with my life and my family dealing with what God has dealt me. He doesn't waste your pain. There is life after cancer with lymphedema", "I am living with this condition everyday but not as an invalid but as a survivor. God spared my life and lymphedema was part of the package. That's OK when you consider the alternative." (Ridner et al., 2012)</p> <p>"The most effective strategies that the women used was to 'give up' or 'let go' of what they could. Ms Lam, a 43-year-old Chinese woman, and Ms Jane, a 63-year-old white woman, used to enjoy putting possessions in different storage boxes or helping others alter their furniture. After several difficulties with worsening lymphoedema symptoms, they made a decision that they had to 'give up doing storage, cutting wood or carpet, sorting things, and fixing furniture for family members and friends'. Similarly, Ms Anna, a 57-year-old white woman, noticed increased swelling and pain in her affected arm each time after she finished her cross-stitching. This made her consciously decide to 'let go' of a hobby that she had enjoyed since her childhood. In another example, Ms Johnson, a 65-year-old white woman, used to enjoy using heavy iron skillets to cook, however, since she noticed increased swelling and pain she had made the decision to instead 'buy the lightweight skillets'. Some women gave up leisure activities, such as sunbathing, hot-tub, whirlpool, rafting, boating or outdoor swimming. Giving up or 'letting go' of</p>

	<p>'what was normal and enjoyable' for them in the past was hard because it involved a conscious decision every time. However, giving up these activities was still an effective and feasible strategy for coping with their limitations." (Fu, 2010)</p>
<p>Re-invention:</p> <p>`My condition is a part of who I am`</p>	<p>"During the past year. I have learned to accept my arm and have begun to wear my short-sleeved shirts and blouses. Previously I did everything I could to hide the arm with long sleeved clothing in order to avoid all the curious looks and questions about what I had done to my arm. Mentally, it feel good now that I have come so far. that I do not worry about it any longer. It is as it is, best to just make the most of it, in other words take care of yourself and your arm" (Lindquist et al., 2015)</p> <p>"[Being] reasonably happy and positive, which is all you can do in these situations. You just have to look for the upside...it may be very limited, but that's what you have to do. Get up in the morning and say 'Hey, that's nice, the sun is shining. And, if it isn't, the sun will come out tomorrow" (Hamilton and Thomas, 2016)</p> <p>"If this is the worst thing I have to deal with is getting over cancer, I'm in! 'C'est la vie' ... suck it up ... I've had a good life! I am not three years old going out to play in the sand. It [secondary lymphoedema following cancer] is not the end of the world. And sometimes I get to do different jobs [when feeling well] ... [however] I have a really sore arm today so I can have a beer with the guys. That's how I work it too!" (Hamilton and Thomas, 2016)</p>

C6. Support Network: Stages and Key Quotes from the synthesised articles

Stages	Key quotes of PLWL from the synthesised articles
<p>Isolation:</p> <p>`I feel my condition is underestimated and I am criticised`</p>	<p>[Healthcare Professionals] "Participants felt let down by the medical professionals they informed about the swelling, as they were neither listened to nor guided in terms of treatment. Participants were saddened by and angry with the responses they received which included "so what?" and "just live with it." Diana voiced her anger as follows: "I visited the doctor once a month and each time I told him there is something is wrong, but he just said 'it will go away'...nobody listens! I hate it when they say it will go away!" "Paula added: "I had to phone my daughter in America to help me find somebody in South Africa who could assist me...oncologists know about cancer but nothing about lymphedema...said there is nothing that could be done to the lymphedema, I just have to live with it..."The participants felt uninformed about breast cancer related lymphedema - not only the risk of developing this complication but also what to do should they develop it. They felt let down by the medical practitioners who treated them as they did not acknowledge the importance of the lymphedema. The medical practitioners did not support participants with information about treatment and expected from them to merely live with this complication." (Maree and Beckmann, 2016)</p> <p>[family] "My son and parents don't see the big deal and think I'm being weird for letting this bother me. [...] They all say, 'Well, at least the cancer isn't back.'" (Ridner et al., 2012)</p> <p>[Social Context] "Participants with lymphedema occasionally encountered critical remarks from others that elicited hurtful, defensive feelings. Two statements are exemplar descriptions of feeling criticised. The first described a comment in which the other person insinuated that her lymphedema condition was her fault: They think, 'Why can't you do better? Why is your arm that swollen?' And it gets very depressing sometimes. And they will make remarks about your arm and why you can't do better with your arm.'" (Ridner et al., 2016)</p>
<p>Recognised:</p> <p>`I'm looking for ways to get more support`</p>	<p>[Healthcare Professionals] "I've been thrown out. The last time I came nurse measured my arm and said it's been the same now, so we don't need to see you unless you have a problem. It's such an insidious progress, would I spot it in time? I don't know. I'm not awfully confident because I don't want to get a fat arm and it was like a safety net - periodically I'd" (Jefferis et al., 2016)</p> <p>[work] "I have to ask for help at work when lifting heavy things and I feel like people just think I am a wimp or something." (Ridner et al., 2012)</p>

	<p>[family] "Well, I [patient's wife] didn't see the therapist doing it. This, it was like him tell(ing) me something that he knew, that I didn't, it was sort of like us going out and him teaching me how to hit a golf ball. So it didn't work, it didn't work very well. I should have asked to go in" (J. Deng & Murphy, 2016)</p>
<p>Collaboration:</p> <p>`I feel supported and connected`</p>	<p>[Healthcare Professionals] "Many described how they were motivated to reciprocate [the support of their lymphoedema therapist] by accommodating lymphoedema into their lives through engaging in self-management: meticulous hygiene, skin care, self-massage, protection from insect bites and trauma, wearing compression garments and taking regular exercise: `Coming here, it encourages you to do all the simple lymph drainage (...) the fact that someone has actually worked on you makes you feel I have got to give something back.`" (Watts and Davies, 2016)</p> <p>[peer support] "When I met the women with lymphedema at the beginning of my treatment, I was motivated. I still apply my cream, do exercise, and take care of myself immediately after I remember those women." (Cal and Bahar, 2016)</p> <p>[family] "[my wife] was always with me when I went to see x [lymphedema therapist]. So, uh and and uh x [lymphedema therapist] recommended that that she be there as well. So that uh, not only he could teach both of us. Then x [my wife] could be the one to encourage me to make sure that I did them...She, she uh uh, did some of the uh uh did some of the therapy on my chest and different, um just, I can't uh." (J. Deng & Murphy, 2016)</p>

Appendix D – The scenario for interviews with PLWL

What if...

Peer Support:

Susan, who had lymphoedema for a long time, called Abby for a chat last week (5). Abby was relieved to hear that she is not alone and there are ways to cope with it from someone who managed to do it herself.



Digital Social Network:

She had also written to the online forum about the new compression garment that she had read about. Her friends using it seem to be very happy with the results (6). She decided to talk about that with her lymphoedema therapist.



Group Follow-up Appointments:

She also received information about the option to have her follow-up appointment with a group or individually. After talking to Susan, she is looking forward to meet others in the group (7).



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What if...

Goal Setting:

Abby had set her goal to increase her activity, yet she couldn't find time to exercise today. She checked her stats and decided to walk during lunch break (8).



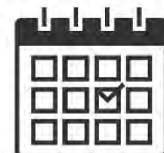
Personalised Newsletters:

She received her newsletter. This month it's about the new research done about the lymphoedema surgery, and tips for staying elevated (9).




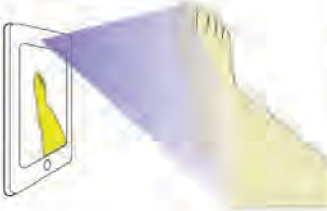

Lymphoedema Calendar:

She got a reminder about her appointment today. She also saw the support group meeting next week, an upcoming workshop for lymphatic drainage massage and an opportunity to try the new lymphatic pump system. She signed for them all (10).




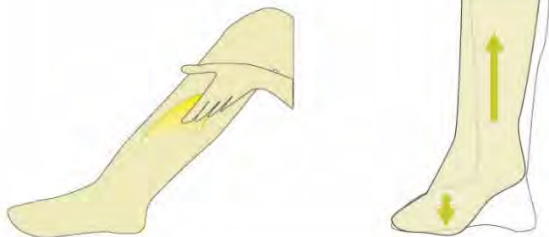
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What if...

<p>Lymphoedema Therapist Appointment:</p> <p>Abby went to the clinic. She showed her picture journey, activity stats and compression levels in the last 6 months (11). They discussed about the possible reasons of the flare up two months ago and advices to cope with them if happens again in the future.</p> 	<p>3D Scanning for Measurements:</p> <p>Her therapist used a device to take measurements of her leg and ordered the compression garment according to that data (12). Abby's leg hasn't changed since her last appointment which is great news!</p> 	<p>Online Communication with Lymphoedema Therapist:</p> <p>Her therapist told Abby that she doesn't need to wait for another 6 months if she needs help. She can ask questions online, can share stats like the changes in the circumference of her leg or request to be called (13).</p> 
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What if...

<p>Feedback from Compression Garment</p> <p>While Abby was watching TV at home, she saw her compression garment glowing gently as if it was doing lymphatic massage (14). She wanted to check the videos to be sure that she is doing it right, as her lymphoedema therapist showed her.</p> 	<p>Lymphatic Massage and Exercise Guidance</p> <p>She changed the TV channel to massage & exercise mode. While she was doing the massage, she can see her movements compared to the video version (15). She is actually doing it quite well! Then she also completed her exercises with the live video feedback.</p> 
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Appendix E – Supporting Material for Chapter 5

E1 - *Competence: Stages and Key Quotes of Interview Participants*

Stages	Key quotes of Interview Participants
<p>Novice</p> <p>They told me to manage my condition by doing these.</p> <p>I'm not sure how effective they are.</p>	<p>"If you didn't have it [information]. If you go back here [pointing to the beginning] you're in a wilderness..." (Sarah)</p> <p>"In the beginning you don't know if you're doing it right. Something you've never done before, and you have only two sessions in a year. They [lymphoedema therapists] are quite busy. Once in every six months is really now enough contact. Especially in the early stages of lymphoedema and while you're floundering if you're doing it right or not... Someone mentioned a cage... to put it on. I have to find out myself, or come across, or ask or have to look after few thing my daughter looked after. I should have access to such information, there is this gap" (Margaret)</p> <p>"Did she actually demonstrated the, explaining something can be misinterpreted? If can be demonstrated as well as explaining, then it won't be open to misinterpretation... May or may not be straight forward... For example if you're creaming a leg and most people might be starting at the top and going back. It was explained but not demonstrated, you would forget it. No one showed me... [How about videos?] You got no idea how it would feel... I have an example for that, when you get your garments you know it would fit your leg and will give a compression. But then you could be given a form of a wrap. It's similar to a garment, but you could change the tightness. But they don't tell you how tight. Then I pulled it quite tight. When I showed the leg the next day, they said it's too tight. Then I had red lines, but nobody tells you... and I did it for a couple of weeks, but I was waiting for the new garments, I wear them to bed and obviously, because the leg goes down during night I pulled it quite tight. But they didn't tell me how tight it should be in different scenarios. during the day when you're moving you can adjust the straps, you won't pull it too tight, but overnight if you're wearing it to bed, do you do it as tight as the limb at that time if you look during the night the garment would be loose...it's different... when you're wearing it to bed it's different" (Elizabeth)</p>
<p>Experiential</p> <p>I explore new ways to better manage and observe possible triggers.</p> <p>It's a trial and error.</p>	<p>"But once you have the information. If you're really positive about it. You use that information and work with it. Definitely you would use the skin care, self-massage, what to do what not to do. Even the one about not to take the diuretics. I took those before, but nobody knows it before. Good information is very important... It's just being inquisitive, isn't it? I started going to different conferences and talking of different groups. If I want to visit somebody, I would go and visit the support group in that area" (Sarah)</p> <p>"That [finding the right tools for self-management] has always been hard. It's done between the conversations with your therapist. Once you got that, then you work with it. It doesn't stop you to searching the information online. it's about learning as much as you can in relation to lymphoedema, it's about learning the different tools of management" (Elizabeth)</p> <p>"It's just about drainage. I do put a cushion under my legs. It came about because my husband needed an adjustable bed, so we got an adjustable one to help my leg. I was lucky because I knew about it, but no one really pointed that out to me." (Lesley)</p>
<p>Expert</p> <p>I can manage my lymphoedema.</p>	<p>"I do more things now. I try and do more. I say well I try it. They said vibration but I wasn't happy about the vibration plates, so I tried that roller. I just felt they were too much. There are also suction cups I use those as well. My therapist use it and she said... I buy that as well. If I find an area that's hard, I work on that. It's a matter of trial and error... keep trying different things. Some sort of routine, try walking swimming exercising in water. Different stretching. If my ankle swells, I try to wear my wraps, I try using the suction cup. Try to target specific areas. Because you don't get anything from the NHS. You don't get MLD or anything... You got to keep. And if one thing doesn't work you got to try something else and keep</p>

<p>I always look for new strategies to better manage.</p>	<p>swooping and changing. This hot weather, I have been wearing the thick garments that I wear. I have been draining more I have been using this roller massager. But it's going up in my hip more and staying there. So, I don't want to collect it in my hips and have a problem there, I have been wearing one leg panty hose types. I have been wearing that to bed instead of just thin stocking. You have to just think, hang on, this needs a compression, and it's not just going to work in the day, so I wear all night. You just learn to read things and work out what is the best for you. Elevation is one of the best things." (Mary)</p> <p>"Finding the right tools takes time. You have to fail and try things. You have to try different things. I'm always trying different things. There is always new stuff. Great technologies coming along, like the night garments. You have to try.... it's an evolving condition and you need to evolve with it. You can keep it to that level, but you should be one step over it. Why is my leg suddenly not responding to it? It is because.... problem-solving." (Laura)</p> <p>"It's about being able to assess and just forming a habit of knowing possible reasons of you're up or down but looking after yourself at the same time. It's about learning the different tools of management... We could always look at it and say, oh yeah, it's gone down a little bit today or oh yeah it's gone up a little bit today. I'm analysed the reasons why and what if I have done something different. If my measurements change after 6 or 8 months, well actually you got to do something about it. I made me change my meals slightly smaller" (Elizabeth)</p>
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E2 - Autonomy: Stages and Key Quotes of Interview Participants

Stages	Key quotes of Interview Participants
<p>Amotivated</p> <p>They told me to manage my lymphoedema.</p> <p>I wish someone could do this for me.</p>	<p>"The exercise and simple lymph drainage, they say it is [simple lymph drainage] the best thing you can do but I often wonder how effective it is to get fluid from... Long way from the leg. I don't know how effective it is. Sometimes I do, I'm at a phase and sometimes I do religiously and sometimes I forget. I'm not as dedicated as I was at the beginning" (Carol)</p> <p>"Getting used to wearing the stockings and getting used to wearing compression is the most challenging. Especially when... Yes I needed it but it wasn't as bad as it is now, because I would think "oh do it without it for a day or so..."` (Jennifer)</p> <p>"Sometimes I wake up and I'm not in a mood to dealing with my leg. Sometimes you got to motivate yourself, like exercising... Patients always are looking for very easy solutions... It can be that you got very good results at the beginning and then it slows down" (Helen)</p>
<p>External and introjected</p> <p>I feel guilty if I don't manage my condition.</p> <p>I'm doing these because I'm afraid of the consequences.</p>	<p>"I know I have to do it, and I feel bad, but I do it. I feel guilty, that's one night, that I didn't put my garment on, and I felt guilty. It's probably a good thing" (Laura)</p> <p>"It's about continuing to do the self-management. Basically, being a good girl and doing everything that's told. It's probably simple, just keep doing it. And I'm not an angel, I don't always do it. Most of the time I do". (Lesley)</p> <p>"I'm also going to the breast friends. A lot of people with arm problems. Their hands and arms swollen like elephantiasis. That's exactly what I want to avoid. I want to keep it under control. When it does get out of control, it gets absolutely horrendous and gets uncomfortable, hot and obviously look very odd." (Margaret)</p> <p>"Sometimes I'm more motivated but other times... you keep going and going. I guess when you get good results then you feel more motivated, but if you are slogging away and nothing is happening, and you start to think this is not working. You lose a bit of your mojo. When you see things are working you feel more motivated. Sometimes I think, let's try something else. Sometimes, it's very difficult." (Mary)</p>

<p>Integrated</p> <p>I'm managing my condition because it's important for me, it corresponds to my goals and is a part of my life.</p>	<p>"Why did it take so long for the bandaging to be effectively? It should have worked quicker. What am I looking at? My optimal should be 30%... I needed smaller. I was quite active, and it was effecting my sports. I'm too young, I'm too fit. I need to do something" (Elizabeth)</p> <p>"Self-management is to prevent me to get cellulitis. That's the main thing. I know that when I don't have my stocking my leg gets swollen, and I know that then I'm more prone to cellulitis, a kick or a scratch. My goal is to remain cellulitis free, is to prevent infection in the leg, to prevent it getting any worse" (Jennifer)</p> <p>"You can't relax. You can't slow down. You can't say I'll get a week off. It just creeps up and gets bigger. You got to keep. and if one thing doesn't work you got to try something else and keep swapping and changing" (Mary)</p>
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E3 - Habit: Stages and Key Quotes of Interview Participants

Stages	Key quotes of Interview Participants
<p>Intention</p> <p>I try to manage, but I feel like I cannot always...</p>	<p>"If you're a busy person, and I was extremely busy until I retired... In those busy years, my self-management probably suffered a little bit. Perhaps I didn't do my exercises twice a day, or every day. I can't remember now. But it was certainly hard to try to fit it all in." (Lesley)</p> <p>"It's quite time consuming and obviously with appointments and things... If you got an early appointment like today, I had it at 8.30, so you don't get time to do it properly." (Mary)</p> <p>"You have got to discipline yourself and do it. That's why I'm still angry I guess, because you got this, and you got to manage for the rest of your life." (Carol)</p>
<p>Adhesion</p> <p>I strictly follow what I was told.</p> <p>Experiential</p> <p>It's a trial and error to find the ways to manage with minimum effort</p>	<p>"Some people obviously leave it off, but I'm in the situation that I'm too frightened to leave it off. I keep it on constantly. maybe I should put some cream on and put it off for a couple of hours" (Margaret)</p> <p>"Getting used wearing the stockings and getting used to wearing compression is the most challenging. Especially when... Yes, I needed it but it wasn't as bad as it is now, because i would think oh do it without it for a day or so... it didn't get too bad. The challenging thing is now that I need to always wear it." (Jennifer)</p> <p>"Habits of self-management is about, making it easy for starter. Bandaging was too much; I just need to make it a lot easier... I tested and tried and took years. First of all, to make it a habit that you're happy with, it should be easy... finding the right tools takes time. You have to fail and try things... I'm always trying different things. There are always new stuff great technologies coming along, like the night garments. You have to try.... (Laura)</p>
<p>Balanced</p> <p>I adapt and integrate my management to everyday life. I don't let my condition to take over my life.</p>	<p>"Everyone has their own little routine. Just try and fit it in. One that works for someone, might not work for others to fit it in everyday life. Sometimes trying to fit in walking or something else. I sometimes, I say I don't take the car I take the bus then I walk to the bus stop. That just helps to fit in a bit of an exercise. I have been trying to go off with the bus and walk back. That just helps to fit in a bit of an exercise. Trying to manage around... Elevate your leg. With your legs you have to elevate your legs and watch the television. Even if you lay down on the floor and have your legs up against a chair or something. Your legs are quite elevated than, you can watch the television. Just make that time for yourself to rest. That's what I do. Instead of stressing about what I can't do, I lay down and do something else" (Mary)</p> <p>"Sometimes it's constant and tiring. I like going to garden shows. After few hours, your leg starts to ache. It's tiring. Yes, it's. I think you just have to adjust. But if you really what to do something you do it... But you're always aware of it. Because it's not like your normal limb. I can feel my foot now. I can actually feel my toe hurting me. It just doesn't stop me doing</p>

	<p>anything...Time consuming and you have to be very careful that it doesn't take over your life... Although we have the support group, it doesn't take up much time. but you still. you got to not let it be a major part of your life... wearing the hosiery first thing in the morning and stay until the evening. I don't walk around in the morning without the hosiery. I have a shower and spend some time creaming and massaging the leg and I also put some toe gloves over the night. Sometimes I put some extra just little ankle wraps. and I have some bandages wraps. But sometimes those disturb my sleep, so I think taking a good night sleep is more important than because it's not pain but it's there, you're conscious about it and you ache when it goes down strangely. So, that's really my day... I suppose I do without thinking. I do. I would never not cream my legs. When I go on holiday I would cover for sun, I wouldn't just sit under the sun. I still wear my stockings. You have to work on it and it's constant. Some people say that they leave their stockings off, but I've never done that... I would never not wear my compression garment." (Sarah)</p> <p>"It's like a diabetic getting medications, you just remember to do it. Always using the cream for the skin cream, it's just second nature now. [How long does it take?] it only takes 10 minutes for me; I don't spend long time on it. Otherwise, it takes over your life. you can't. you got too easy up. Don't let it take over your life... put stockings on" (Carol)</p>
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E4 - Psychology: Stages and Key Quotes of Interview Participants

Stages	Key quotes of Interview Participants
<p>Overwhelmed</p> <p>I'm sad and angry about my condition.</p>	<p>"I see and know people who have lymphoedema and very close to being in denial about it. If they go to treatment, they need to admit that. I think that's quite a big burden. If you don't want to believe or accept, whatever the right word is, that you have this problem. then you're going to find it difficult" (Lesley)</p> <p>" But you know I get angry, I still get angry about it. They have given me something that I didn't know about and deal with it for the rest of my life with disgusting stockings. One leg bigger than the other, you feel a little aggrieved, I've got cancer and all that and they give me this. so, I still get very angry and upset about it... I'm still resentful after all those years, if I see that surgeon, I would say it to his face." (Carol)</p> <p>"Psychological part is very difficult... extremely depressed. Cope with those sorts. Lymphoedema take... I was very positive about cancer, and it was life threatening but lymphoedema is not why is it causing so much anxiety stress and concern. I can't answer that, I don't know. But I cannot accept it. I'm having difficulty in accepting lymphoedema. I accepted cancer, five weeks after I was in the beach; I was fine from the very beginning. Lymphoedema was very bad for me. The others are fine, but not about the acceptance." (Margaret)</p>
<p>Reconsidering</p> <p>I know my condition is permanent, but I still get upset when symptoms increase, or someone asks about it.</p>	<p>"The point is it's not just for today it's not just for tomorrow, it's for the rest of your life. It's long term... It's not like having a Measles. You know, if you stay in bed for a while, do everything your mother says and within a week it's over. It's not like that. You have to take that on-board. Some people find that very difficult. I have certainly met people who work in the principle that if I don't say it and if I don't acknowledge it won't happen, but of course it does" (Lesley)</p> <p>"In my case, I got treatment straight away, I got compression tight straight away that helped all down. It was like that for few years, just going to the clinic and checking in. and getting new tights. But all of a sudden, my right leg just started to swell for absolutely no reason. Because I was always careful with my skincare and look after them, and that's when I got miserable. One leg became bigger than the other, which I hate. " (Carol)</p> <p>"When it does get out of control, it gets absolutely horrendous and gets uncomfortable, hot and obviously look very odd. Walking around with a really big big arm. Which is partially the</p>

	look. Partially, that's when say 'What happened to your arm' and then cancer again. I don't care what people think about me but that brings a memory that I want to forget about." (Margaret)
Coming to terms with I accept my condition and am positive about it. I get on with my life as normal as possible.	<p>"You got to learn not to dwell on it too much. Try to do as much as you can. Not letting it take over yourself. Being aware of it but still getting along with your life... Probably when I was younger, I was more emotional with it. There comes a point where you got to get along with it. It is the constancies of it, you are living with it. So, your life takes over in a way. You're bringing up a family, you're working that takes priority. Take care of family members, because you're so busy. You don't always look after yourself. There can be moments like as long as you wear your stockings you go to clinics. Just get on with it, you don't get much time to do it." (Sarah)</p> <p>"It clicks in with habits... If you do self-management regularly, if you put it in schedule of your day. As I have exercises to do I do them in the morning before I put on my clothes and I do them before I go to bed, if I'm not too tired. But I know I'm always doing them. It takes around an hour... It's trying to get it, so that you accept that's how your life is... First here, then I'm going to sing and then I'm going to pick up my grandkids. So, I know I'm going to do a lot today and will be in pain but I don't mind" (Lesley)</p> <p>"Sometimes you think you can keep going as you used to. It's accepting it and adapting and pacing yourself. You have to learn to pace yourself. You have to learn to read the signs when your body needs to rest, because if you don't rest you just make it get worse." (Mary)</p>

E5 - Identity: Stages and Key Quotes of Interview Participants

Stages	Key quotes of Interview Participants
Disruption: I'm embarrassed	<p>"They have given me something that I didn't know about and deal with it for the rest of my life with disgusting stockings. One leg bigger than the other, you feel a little aggrieved, I've got cancer and all that and they give me this. So, I still get very angry and upset about it... It takes months to recruit someone, and train them... and it's people's fat legs, it not that exciting or nice is it, to people's horrific legs... It's not a very attractive job, I guess. it takes a long time to" no one is looking at your legs, but I'm really, I don't like it. I find it awful hard to have one leg bigger than the other. I hate it. I won't wear skirts. I just hate it. I don't think I can get over that. My husband says don't be silly nobody is looking at your legs. But because I'm attuned to legs if I'm at a bus queue or a supermarket queue... I've always look at legs, and she has got lymphoedema. But you can tell, I'm like oh she should have some support stockings. Stupid shoes, why are they in improper shoes... this is in my mind. You need a proper pair of shoes to support that foot..." (Carol)</p> <p>"There is not a huge difference, but I'm self-conscious of it. I couldn't get rid of that, If I don't wear my stockings for a day. To me, it really looks ugly. Because it's so discoloured. There are psychological aspects to it. It's about not being quite normal or not being able to do the thing you want to do. Like you can't bend or knee. It's sitting in the certain position; you can't cross your legs. All those things... it can get in the head of it... I don't want it to get so big that it really is noticeable. It's not because I'm vain but I suppose I am. I don't want to stand out because of a grotty leg" (Jennifer)</p> <p>"Symptoms started when I was a teenager. I always thought why I can't wear nice shoes. I couldn't put the straps on... You don't tell people about it. And those days, you couldn't. When I first went to interviews, I had to be very careful by wearing trousers. People would expect you to wear a suit and a skirt. But I always wanted to wear trousers and the other problem is they are quite narrow and would be looking for the wide ones. and the long dresses" (Sarah)</p>
Re-thinking:	<p>"When it does get out of control, it gets absolutely horrendous and gets uncomfortable, hot and obviously look very odd. Walking around with a really big big arm. Which is partially the look. Partially, that's when say 'What happened to your arm' and then cancer again. I don't care</p>

I'm looking for ways to hide my condition, even if that limits me.	<p>what people think about me, but that brings a memory that I want to forget about" (Margaret)</p> <p>"How am I going to be able to do all the things that I used to be able to do and carry on. How can I still fit in? Where can I find clothes that I can fit in and feel good in?" (Elizabeth)</p> <p>"Before the hosiery it was visible and people would say your feet is swollen, and you have to explain them you have a problem with swelling. If I look back in the photographs. I tuck my feet under the chair. Because you don't want your feet to be in the photographs and I've looked at some photographs and you come across and I can see that my feet were swollen. so probably I was sitting there trying to hide my feet... the way you dress. I don't want to walk a room and people say, oh she's got lymphoedema. I don't want them to know, they don't need to know." I think that's how you sort of cope." (Sarah)</p>
<p>Re-invention:</p> <p>My condition is a part of who I am.</p> <p>I'm confident about myself with my condition.</p>	<p>"You have to take care of yourself. Part of self-management is about taking care of yourself. Ensuring that you look good and feel good. Ensuring that you're confident in your own body" (Elizabeth)</p> <p>"You might be shameful. It can be... Like you don't want to show your legs to your husband. I know some patients that they don't want to take themselves out... I'm in a lot of patient groups and you see the differences. They are very much communal but want to look good all the time. I'm posting my pictures with sandals, and they are like oh I would never do that, you know they never go to the beach. Wouldn't go swimming, wouldn't wear a bathing suit. It would be absolutely... they would be horrified about the idea. I have been... I would be going to beach. This is important" (Helen)</p> <p>"It takes a lot to come to terms with it. Even then it takes time to become confident with it. It knocks your confidence. Today I wear sandals. This is the first year I wear sandals and show my stocking. Because I was so conscious of it, I used to buy shoes that would cover up my legs, boots. I wouldn't let my feet to be seen... You got to build up your confidence with it" (Mary)</p>

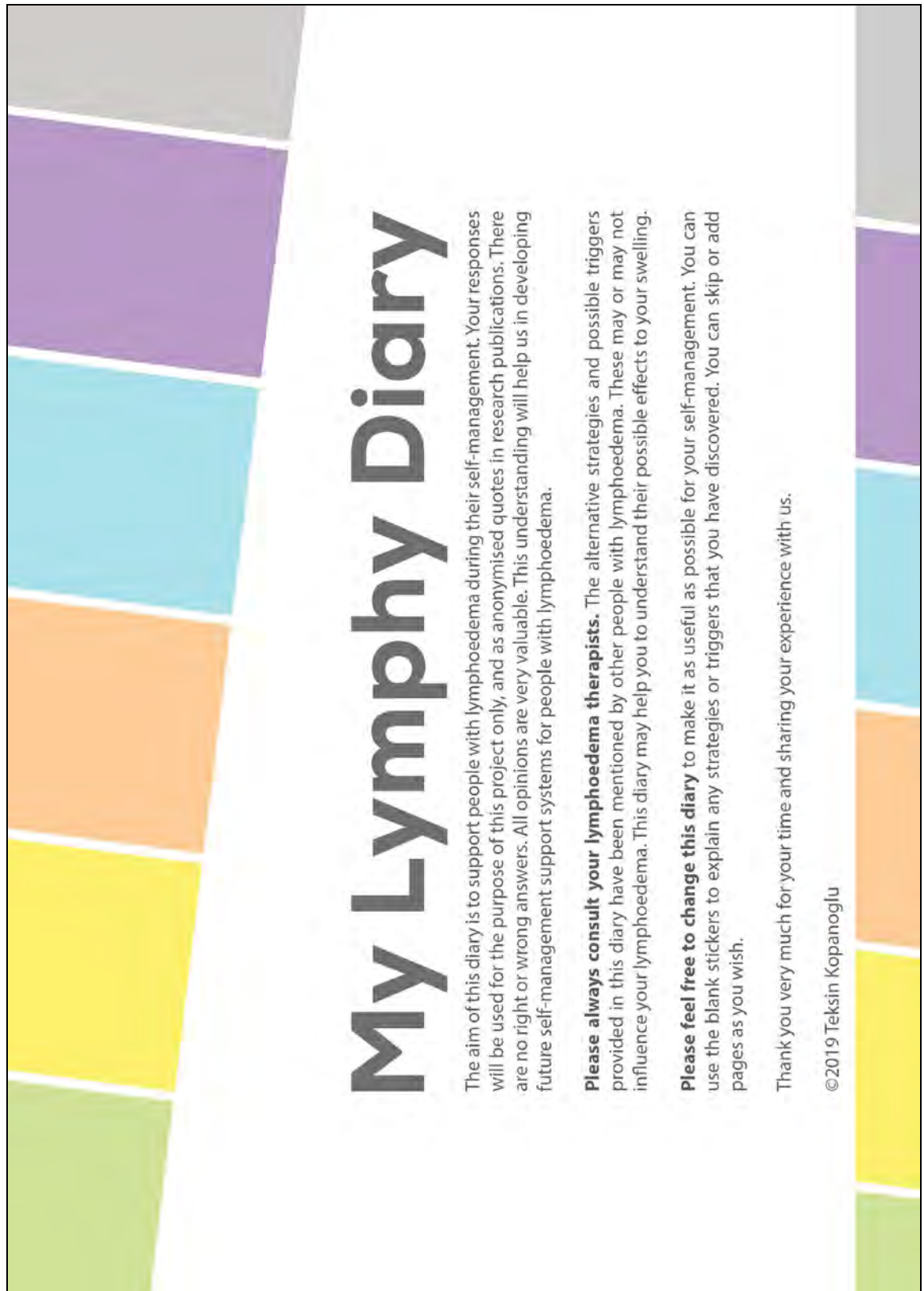
E6 – Support Network: Stages and Key Quotes of Interview Participants

Stages	Key quotes of Interview Participants
<p>Isolation</p> <p>I feel my condition is underestimated and I am criticised</p>	<p>"Lymphoedema is something else. I don't tell anyone really, because they wouldn't understand, they would say 'can't you just drain it'. 'Couldn't you just take a water tablet?' 'Lymphatic system, proteins and things...' 'oh does that mean you can't eat meat'. It's not something they understand... Lymphoedema wasn't mentioned before surgery... I found the lymphoedema diagnosis worse than the cancer. A lot harder than cancer. Because it is something I've never heard of, and I knew nothing about and something they given to me. You see, through this treatment and they've never mentioned it. I often think that if they have mentioned it because if I knew how it was all like I would not have the operation. They said we have to remove the lymph nodes because the cancer could spread, but you know I get angry, I still get angry about it. They have given me something that I didn't know about and deal with it for the rest of my life with disgusting stockings" (Carol)</p> <p>"I don't think there is enough support. I think different cancers and different illnesses get a lot of support. But we don't seem to get anything. I'm sure there are a lot of people who haven't been diagnosed and don't know... I didn't know anything about lymphoedema. Never heard about it. When surgeon said chemotherapy or radiotherapy... another surgeon said 'oh you have radiotherapy' and he was a bit hesitant. He must have known lymphoedema will be risk. Nobody mentioned any risk of anything. They do now but they didn't at that time. I didn't know until I had it, but it did get quite big. It's the trouble when you get it, you can't get rid of it" (Mary)</p> <p>"It's a funny condition, it's really difficult to explain it. Some of them would say just a little swelling wouldn't they... you tend to not give much detail, because it's really hard for them to understand... Then getting that to look. I never told it anybody. I never wanted to talk</p>

	<p>about it. So, I sort of then get very involved in my work and enjoyed it with children growing up. you can't talk about it because people will look at me and say there is nothing wrong with you... At the beginning, there is not any support. When you first meet other people with lymphoedema... because they understand. And a lot of patients will tell that it's good to talk to others with the condition" (Sarah)</p>
<p>Recognized</p> <p>I'm looking for ways to get more support</p>	<p>"...she called me one day and she had found a leaflet, and somebody told her about it. And we thought 'oh gosh a charity and somebody is actually talking about it'. And we went to the charity... I started going to different conferences and talking to different groups. If I want to visit somebody I would go and visit the support group in that area...I got to know them so well. Because I used to go to conferences and so know them socially as well. They are still good. So, you learn, read the articles. I do, but not everybody bothers. Keep up with what's happening." (Sarah)</p> <p>"Hidden miss and what you come up with yourself. As a patient... If you put your stockings in the fridge and then they are cold... and that helps with the heat. I heard about it in the support group and also your skin cream. It's then nice and cold in the heat." (Carol)</p> <p>"We chat, lymphoedema support group, and breast friends... So that's quite good. Still, I need to talk to somebody with the knowledge.... They [other people with lymphoedema] just get experience. They are experiencing it as I'm experiencing it. They don't have the proper knowledge... If I'm with my main friends, I don't really want to talk about my problems my bits and pieces. Happy and talkative... When we are in this group we can then talk about our problems. We are sharing then. I have very supportive friends, but I don't want to talk about my problems with them. Lots of problems with family, it adds a little bit of stress. My granddaughter is extremely supportive. She would ask how are you and I would say I'm fine." (Margaret)</p>
<p>Collaboration</p> <p>I feel supported and well connected</p>	<p>"I am going to the lymphoedema support group. I've made good friends and met good people and sometimes we're a nice little group. Sometimes support groups can be very difficult because people come with their own agendas, you know perhaps their experience with their GP... We're not about that, we're not a focus group or a pressure group. We just chat about fat legs and garments..." (Carol)</p> <p>"I would like to know that all eventualities are talked through. We would try and understand and talk about why things don't work for me, that's really very irritating. I work hard trying to make my legs better, then I need to know that I'm trying all the right things. I mean, I know and I do try hard very hard filling, to trying to my way down further" (Lesley)</p> <p>"I think when you get together as a groups that can motivate you. We got a small group, and we sort of motivate and help each other" (Mary)</p>

Appendix F – Supporting Material for Chapter 6

F1 – My-Lympho-Diary for Lower Limb Lymphoedema





"You always set up with the compression
and then you find the things to add-on..."



"I was so convinced that my leg was getting
bigger... They measured and said 'no, it is actually
smaller' but it's got bigger in different areas"

I feel better when ...

(might) make my
lymphoedema
better because ...

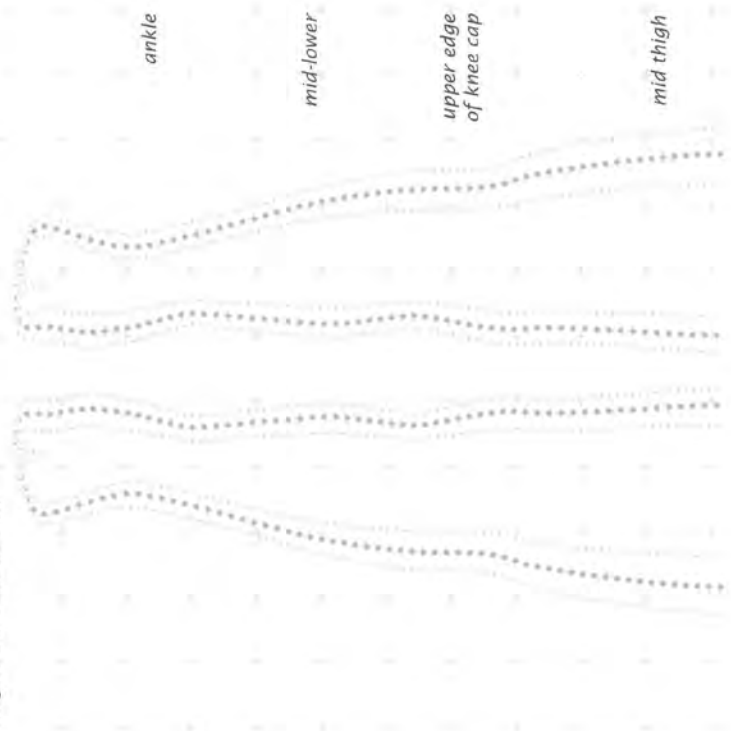
(might) not affect
my lymphoedema
because ...

I feel ...



It looks ...

...compared to...

Might be because ...



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 I analysed the reasons why and what if I have done something different	 You carry on with the same treatment for such a long time that you don't realise...
I don't feel well when ...	I feel ...
<div data-bbox="738 1442 853 1944" style="border: 1px solid red; border-radius: 15px; height: 100px; width: 100%;"></div> (might) trigger my lymphoedema because ...	It looks ...
<div data-bbox="1061 1442 1176 1944" style="border: 1px solid red; border-radius: 15px; height: 100px; width: 100%;"></div> (might) not affect my lymphoedema becausecompared to...
<div data-bbox="1353 1816 1385 1944" style="border-bottom: 1px solid black; width: 100%;"></div>	Might be because ...



"I don't always succeed, but it [goal setting] makes me do more... it makes me to think about it."



"Ohh that's gone down a bit, that's good" That gives you a bit of incentive to keep at it, and I'll start doing the lymph drainage then."

I want to ...

I feel ...

My aim is to ...

It looks ...

...compared to...

Might be because ...



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*'It's a matter of trial and error...
keep trying different things.'*



*'Goals to keep you motivated on tasks and to
remind you that this is going to take time...
otherwise you can get very despondent with the
treatment quickly... You need to give it time'*

I feel better when ...

(might) make my
lymphoedema
better because ...

(might) not affect
my lymphoedema
because ...

— / — / —

I want to ...

My aim is to ...



‘Try to do as much as you can, but not let it take over yourself. Being aware of it but still getting along with your life.’



It's about learning the different tools of management.
How can I formulate my own programme?

I feel better when ...

— 10 —

(might) make my
lymphoedema
better because ...

1000

(might) not affect
my lymphoedema
because ...

1/1

My plan is ...



‘It’s about being able to assess and just forming a habit of knowing possible reasons of you’re up or down, and looking after yourself at the same time.’



‘It’s time consuming and you have to be very careful that it doesn’t take over your life.’

I don't feel well when ...

— 10 —

(might) trigger my
lymphoedema
because ...

100

(might) not affect
my lymphoedema
because ...

1/1

My plan is ...



'If you are swooning away and nothing is happening... you think, perhaps I'll try something else or what else can I do...'

I feel better when ...

(might) make my lymphoedema better because ...

(might) not affect my lymphoedema because ...

--- / --- / ---



'Sometimes you feel like you are doing something endlessly and not seeing the results fast. Lymphoedema comes down to time. It's not a fast thing to change.'

I want to ...

My aim is to ...



*"You build up confidence by very small steps.
You tackle one small issue at a time."*

*"It goes up and down. Even if it goes up you have to be
still positive. Accepting that it can go up. Especially if
it's particularly warm day or being on it too long."*

I don't feel well when ...

(might) trigger my
lymphoedema
because ...

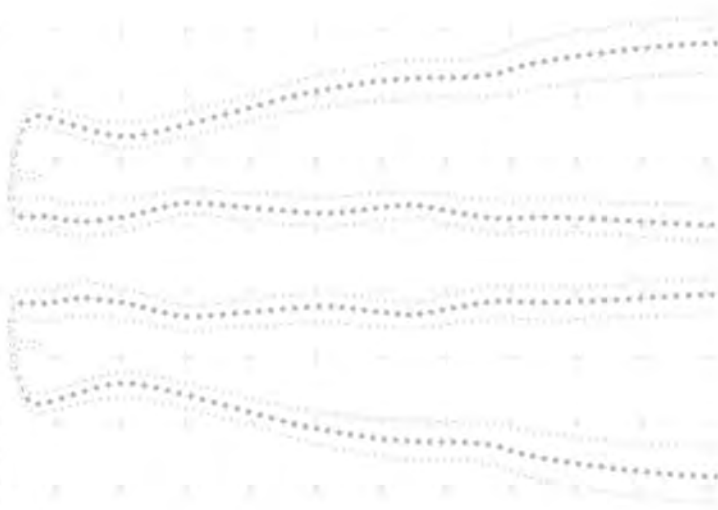
(might) not affect
my lymphoedema
because ...

I feel ...

It looks ...

...compared to...

Might be because ...



--- / --- / ---



'I work hard trying to make my legs better, and then I need to know that I'm trying all the right things.'



'I would like to know that all eventualities are talked through. We would try and understand and talk about why things don't work for me...'

After seeing my therapist ...

I told ...

I felt ...

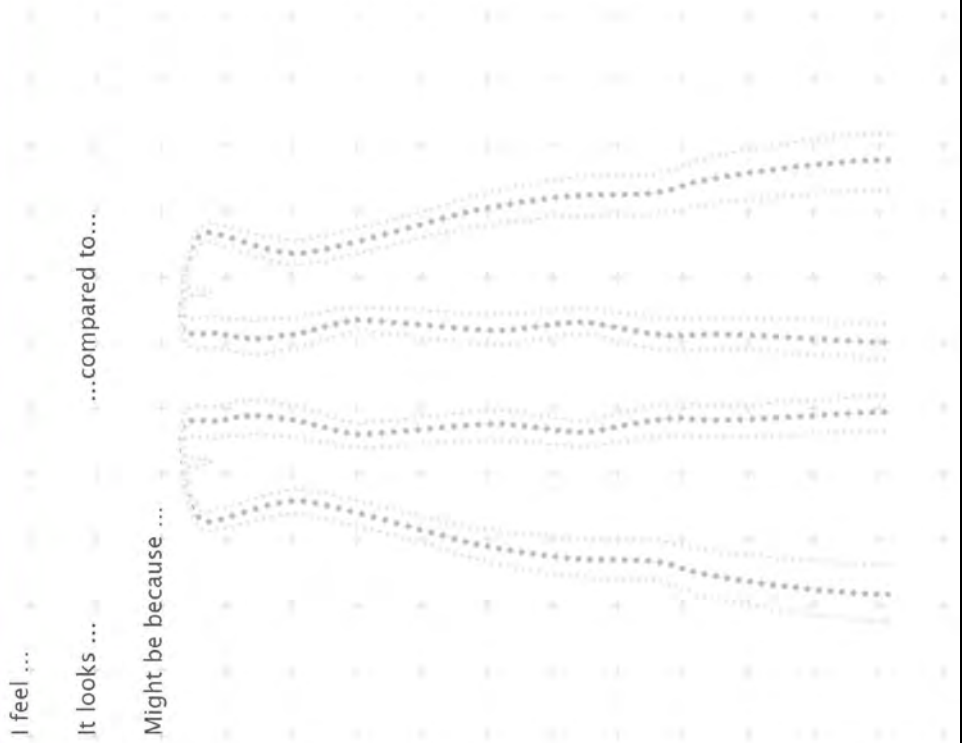
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I feel ...

It looks ...

Might be because ...

...compared to...





Someone to talk to especially at the beginning. That's how you learn tips and tricks. See that you're not alone.



You meet some people that inspire you. Sometimes you see someone and you think I can do that too.

After the support group meeting ...


I want to ...

I told ...


My aim is to ...

I felt ...

--/--/----



Objective Monitoring: Just two or three pin point measurements... if you can show a slight reduction that would build up confidence...



It's an evolving condition and you need to evolve with it.

I do/don't monitor my swelling because ...

I prefer because...

I don't like because...

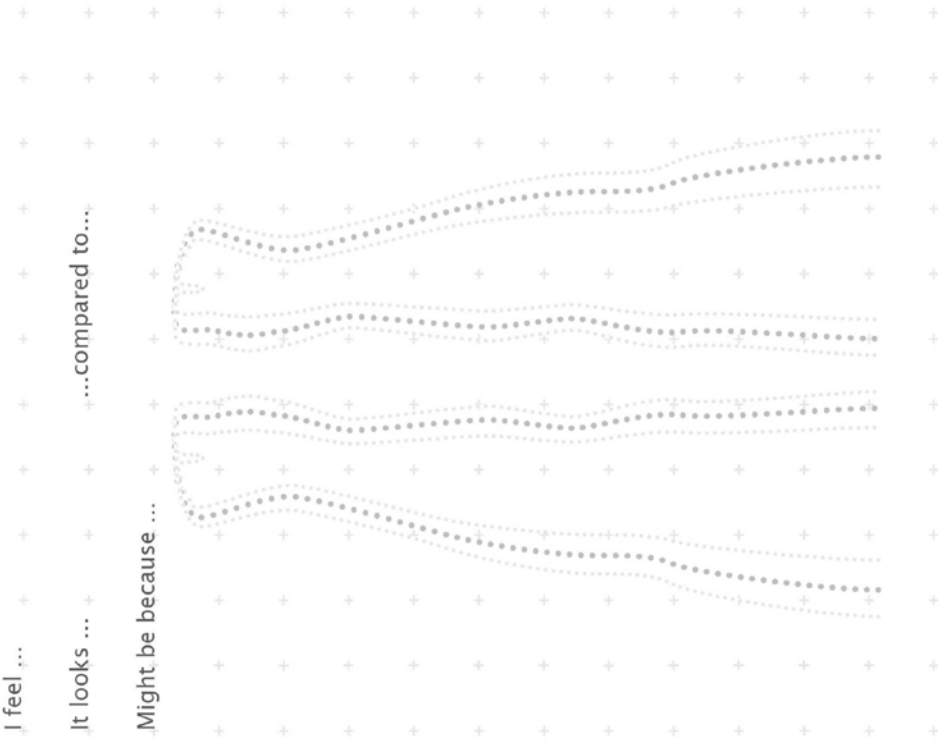
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I feel ...

It looks ...

Might be because ...

.....compared to...





Subjective Monitoring: Don't focus on measurements, but how you're feeling and looking and if you're able to put shoes on.



It can go up and down in different areas because it depends on the time of the day. Mornings, evenings, if it's hotter.

I do/don't monitor my swelling because ...

I prefer because...

I don't like because...

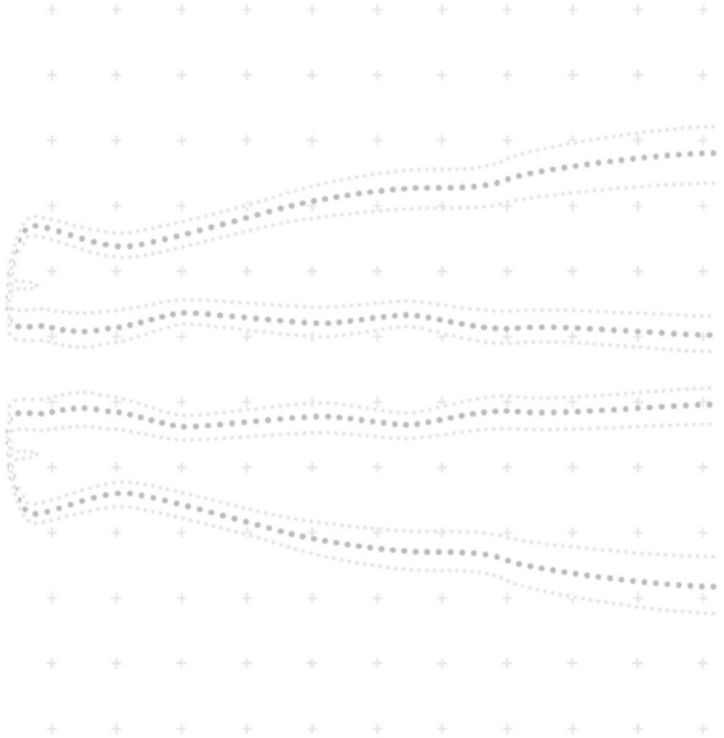
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I feel ...

















It looks ...

....compared to...

Might be because ...



Alternative Management Strategies		Please describe the additional management strategies that you have discovered and add these to your diary	
 <p>Compression</p> <p>"You need the compression. Make sure you're fitted for the compression that's right for you"</p>	 <p>Meditation and Deep Breathing</p> <p>"Abdominal breathing is essential for the return of lymphatic fluid back to the bloodstream"</p>		
 <p>Skin care</p> <p>"I cream my legs everyday. Chapped skin causes breaks that can invite bacteria and infections"</p>	 <p>Have Some Rest</p> <p>"Learn to read the signs when your body needs to rest... just make that time to rest"</p>		
 <p>SLD</p> <p>Simple Lymphatic Drainage</p> <p>"Encourages lymph to drain out. It's important that you're taught by a specialist."</p>	 <p>Elevate while Sleeping</p> <p>"I do put a cushion under my legs while sleeping"</p>		
 <p>MLD</p> <p>Manual Lymphatic Drainage</p> <p>"You can find a trained therapist to aid the drainage of the lymph"</p>	 <p>Nighttime Compression</p> <p>"They compliment day-time gains..."</p>		
 <p>Activity</p> <p>"We need to keep active. Muscle pump is the only pump the lymphatic system has"</p>	 <p>Stockings in the Fridge</p> <p>"If you put your stockings in the fridge and then they are cold... helps with the heat."</p>		
 <p>Hula Hoop</p> <p>"It helps draining the lymphoedema in my legs when I use it daily"</p>	 <p>Dry Brushing Skin</p> <p>"Brushing with a loofa sponge or natural bristle brush can stimulate the lymphatic channels"</p>		
 <p>Swimming and Water Exercises</p> <p>"Water provides pressure and the muscular exercise helps the lymph to flow."</p>	 <p>Drinking Water</p> <p>"Drink eight 8-ounce glasses of water daily and increase your fluid intake in hot weather"</p>		
 <p>Eating Healthy</p> <p>"Eat a balanced, healthy diet that includes whole grains, fruits and veggies"</p>	 <p>While Traveling</p> <p>"Wear compression, move around and sip plenty of water"</p>		

Possible Triggers		Please describe the additional triggers that you have discovered and add these to your diary	
 <p>Busy Days "It's getting really bad when I'm standing for a long time"</p>	 <p>Stress "It looks as if mental things have more influence on the edema than physical" (Vehoff 2015)</p>		
 <p>Cold Weather "...is painful especially when it is cold and raining" (Maree 2015)</p>	 <p>Time of the Month "Would go way up before my period"</p>		
 <p>Hot Weather "During the summer... It can be unbearable painful, when it is hot" (Lindquest 2015)</p>	 <p>Time of the Day "The difference between my legs before I go to bed and in the morning is noticeable."</p>		
 <p>While Traveling "prolonged inactivity and dehydration may contribute to reduced lymph flow"</p>	 <p>Smoking "Smoking affects almost every aspect of your health including lymphoedema"</p>		
 <p>Traditional Massage "Avoid traditional massage on the effected area, try manual lymph drainage instead"</p>	 <p>Alcohol "I know that my legs would be better if my diet could be cleaner, if I don't drink alcohol"</p>		
 <p>Hot "Limit saunas, hot tubs and whirlpools."</p>	 <p>Hair Removal "Careful to not to snag your legs. I use an electric razor; that doesn't pull at all."</p>		
 <p>Bowel Movements "If I'm constipated, abdomen is pressing on my veins..."</p>	 <p>Shoes "I know that my ankle is not good but I know why, because I was wearing high heels."</p>		
 <p>Sunburns "Sun is good, but too much may cause pain, inflammation and swelling"</p>	 <p>Body Position Blocking Lymph Flow "Considered to be a bad practice to have you legs crossed."</p>		

F2 – Self-Monitoring Methods Used by the Participants

	Sarah	Margaret	Mary	Elizabeth	Jennifer	Angela
Tape measurements	NO: “I don’t need a tape measure very often. You know when you are doing the right things” “It does also depend on time of the day when measurements are done”	NO: “I just keep an eye on my arm, and I know when it has become bigger. I try not to become too obsessed with this”	YES	YES: “I’m experienced in doing the limb measurements which over the years I have kept a diary record. I don’t record measurements as frequently anymore as I can now do a very good visual measurement”	YES: “I don’t measure regularly but when I do I compare it to my last measurement” I use 5 measurements	YES: “Prefer tape measure and measure certain points”
Copies of clinical measurements	Not mentioned	Not mentioned	YES	YES: “I always get copies of my measurements we discuss possible outcomes, achievements and treatments...”	YES	Not mentioned
Texture	YES	Not mentioned	“When the tissue at the top of my leg was becoming firmer...”	“I have tried a new treatment [compression pump] so that the tighter area around the calf can be softened”	Not mentioned	Not mentioned
Fit of clothes and shoes	YES: “I have shoes in my wardrobe that have only been worn on one or two occasions”	Not mentioned	YES	YES	YES: “I do measure when I put on a pair of shoes that I have neatly worn and due appear unusually tight or slack.”	Not mentioned

Sensations	YES: “I know how it affects me”. “It can be painful, and you need to address the problem”	Not mentioned	YES: “you always know when the swelling is worse because you feel more uncomfortable, and the limb feels heavier.”	YES: “it can affect the lymphoedema and thus the limb feels tighter and aches more”	YES: “uncomfortable” “My leg R feels tight, even with the stocking on”	YES: It feels better after swimming.
Gauge with hand	Not mentioned	YES: “I do this as a guide to see if any difference in the two arms”	Not mentioned	Not mentioned	Not mentioned	Not mentioned
Appearance	Not mentioned	Not mentioned	YES: “You can also see a difference in a mirror.”	YES: [It looks] “like the ankle is down but the calf is up” [compared to] “the other leg” “When I do look in the mirror and see if the limb has increased...”	YES: “right leg is very much bigger” [compared to] “my left leg”	YES: [It looks] “awful to my eyes” [might be because] “standing too long”
Pictures	Not mentioned	Not mentioned	YES	Not mentioned	Not mentioned	Not mentioned
Weight	Not mentioned	Not mentioned	Not mentioned	BUT “Weight may not always affect my lymphoedema limb because there are times, when I’ve checked measurement”	Not mentioned	Not mentioned

F3 – Reasons for Self-Monitoring as Described by the Study Participants

	I monitor my swelling because...
To see if management strategies are effective	<p>“[trying a compression pump] to see if I’m more comfortable in the warmer weather” SARAH</p> <p>“I have a clear indication if I’m doing the right things or need to try something different” MARY</p> <p>“But if I keep my legs elevated (which I did) the measurements weren’t too different from my norm” JENNIFER</p> <p>[Might be because] “I am not being as thorough with SLD”. ANGELA</p>
To adapt self-management accordingly	<p>“I do more exercises on my arm if I feel the swelling has increased” MARGARET</p> <p>“Sometimes when I feel my leg is getting bigger, I try some other ways to move fluid and do my lymph drainage more often” MARY</p> <p>“Listen more to your body. Having some rest not just at night is something I have had to learn” ELIZABETH</p> <p>“L (30, 42, 46, 59) don’t wear compression consistently” “R (29, 51, 50, 65) always wear compression”. “That acts like a trigger to see if something is going on”. “self-monitoring useful for specific events such as holidays and occasions when she was not feeling well.” JENNIFER</p>
To know when professional help is needed	<p>“Helps to keep at in check. If there is any swelling, I can phone the clinic” ANGELA</p>
To maintain their motivation for self-management	<p>“It [self-monitoring] always makes me work harder to keep it under control especially if I’ve had an increase. It encourages me to keep going and gives me confidence when I’ve had a reduction and makes me feel better about myself.” MARY</p> <p>“I get up each day and take a look, a good look at both legs and think yes today I can do [daily self-management routine and other planned activities]”, “It’s important to me to maintain my lymphatic limb.” ELIZABETH</p>

F4 – Perceived usefulness and actual use of the cultural probe by the study participants for self-monitoring and related quotes

	Sarah	Margaret	Mary	Elizabeth	Jennifer	Angela
Perceived usefulness of Wrap-to-Measure during the co-making workshop	“This is an excellent idea. Much better than a tape-measure. Much easier to check measurements then at clinic appointments”	“This is great because I can’t measure my arm with a tape”	“It is a really good idea”	“The idea of a wrap to measure for new patients is excellent... which should be adapted into clinics and offered to newer patients along with a booklet to record measurement”	Not Known	Not Known
Made a wrap-to-measure during the workshop	NO – “I didn’t make one on the day but I wish I had”.	YES	YES	NO – “I did not make a wrap-to-measure as I’m experienced in measuring”.	YES	YES
Used Wrap-to-Measure	Not Known	YES	YES	Not Known	Not Known	YES
Wrote measurements	Not Known	NO – Found difficult to use.	YES – Only one page	Not Known	YES – Several pages	NO- Found it inaccurate.
Took Notes of the Symptoms	No	No	No	YES	YES	YES
Sketched the affected limb	No	No	YES: only one page	No	No	No
Comments after using wrap-to-measure	Not Known	“Difficult to do this on my own”	“It’s quick and easy to use and ensures the measurements are always taken from the same points on arm/leg” “The only problem was the double-sided Velcro ... better if it was stitched on”	Not Known	“I usually measure 5 points, but for this diary I measured 4 points”	“It is not an accurate measurement” “I found it very fiddly. Prefer tape measure and measure certain points”

Appendix G – Design for Empowerment Booklet

DESIGN FOR EMPOWERMENT

Design guidelines for supporting the empowerment journey of people living with a chronic condition, lymphoedema

For people living with chronic conditions, self-management is daily life itself, not just an isolated part of it dedicated to the medical condition. Designed products and services have the potential to facilitate or inhibit empowerment in self-management. Below is the meaning of empowerment for our study participants with lymphoedema:

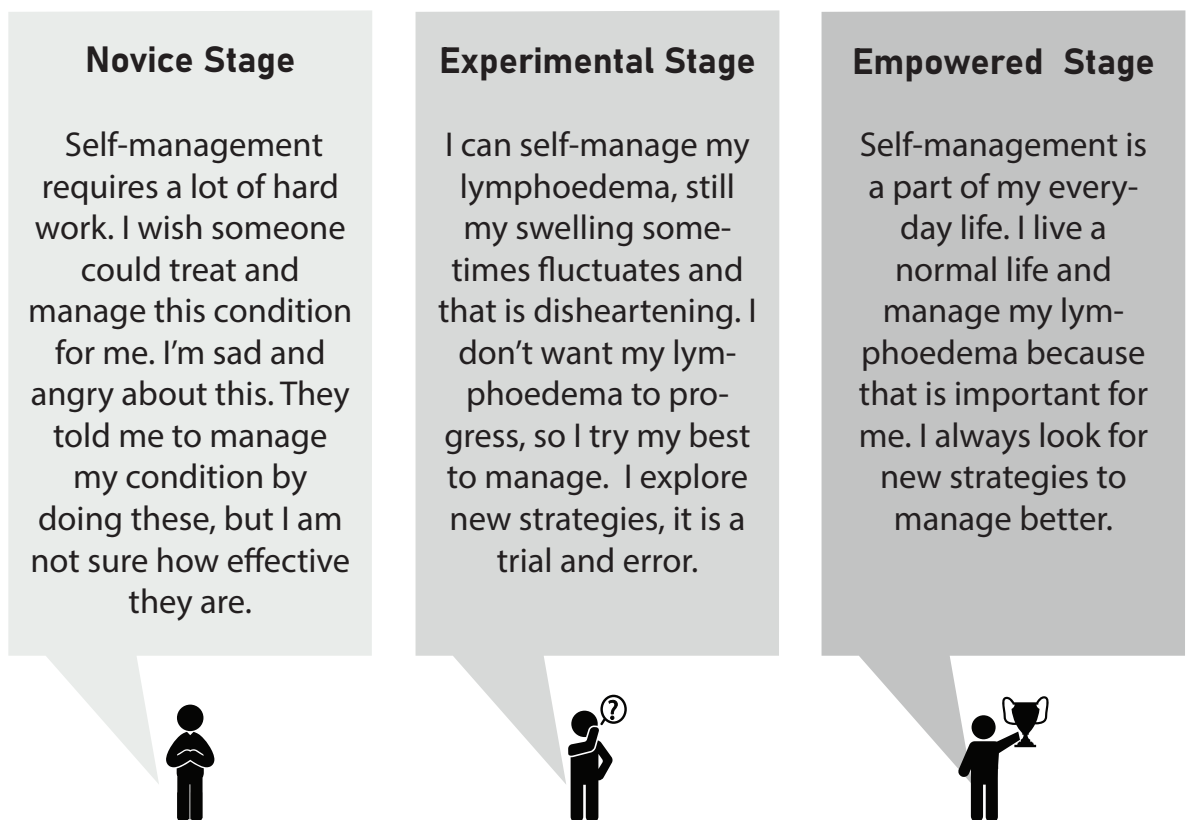


DESIGN FOR EMPOWERMENT

Design guidelines for supporting the empowerment journey of people living with a chronic condition, lymphoedema

Empowerment in chronic condition self-management is a dynamic journey. The support needs of people change depending on their expertise and level of empowerment. The products and systems should be designed to match these changing needs. This study brought the theories about human behaviour and the voices of people living with lymphoedema together, to find better ways to design for empowered self-management.

Three main stages are distinguished in the empowerment journey. Yet, journeys of chronic conditions are as diverse and unique as the individuals experiencing these, and these stages should not be considered as a simplification of this diversity into one typical journey. This categorisation of stages allows creating actionable guidelines to better address the changing needs of people living with chronic conditions and facilitate their empowerment. The three main stage of the empowerment journey are summarised below:



Novice

They told me to manage my condition by doing these. I'm not sure how effective they are.



I'm managing my condition because I have to and they told me to do so.



I try to manage, but I feel like I cannot. I wish someone could do this for me.



I'm sad and angry about my condition.
- or -
Finally, I know what it is, and they said it could be managed.



I'm not 'normal' anymore. I want to go back to my life before this condition.



I feel alone and isolated. Health-care professionals do not understand me.



Design for Novice Stage

SKILLS DEVELOPMENT FOR PROACTIVE PROBLEM SOLVING

Explain the physiology of the condition, underlying principles of management strategies, and why & how these strategies could help.

Lymphoedema is [hands-on and multisensory explanation of the physiology of the condition].

Compression garments [fundamental evidence-based management strategy] can help you because ... [underlying principles of how management strategies are beneficial for lymphoedema].

Start with cornerstones of self-management. Avoid information overload and warn against not-validated sources of information. Be cautious about how advice might be misinterpreted.

There are loads of information online, but be cautious about what you read. I wouldn't do an online search for lymphoedema yet.

SELF-MONITORING FOR WELL-INFORMED DECISION MAKING

Explain why and how self-management can help. Set achievable expectations and explain the time required. Provide simple examples from previous good results.

Keep wearing your compression garments,. You may not feel or see the difference quickly, but persistence is essential to experience the benefits. Would you like to read what Mary thinks about wearing compression garments?

Encourage developing awareness of the related symptoms and sensations. Suggest a simple roadmap to support decision making for possible complications.

If you feel pain or see skin redness [explain particular symptoms in a multisensory manner], get in touch with your therapist.

PERSONALISED GOALS FOR INTEGRATED HABITS

Understand personal barriers against self-management. Suggest an everyday plan to address these barriers, one step at a time.

Is there anything that makes self-management difficult for you? Would you like to try wearing this compression garment [one evidence-based management strategy] for.... [patient driven objectives] It can help you by ... [link to why that strategy might be beneficial]

COLLABORATION FOR WELLBEING AND ADAPTATION

Understand the psychological and social state. Provide guidance for seeking further professional support. Share success stories of other people living with the condition.

There are many others living with lymphoedema. Would you like to read how wearing compression garments allowed Amelia to continue a fulfilling life that she cherished...? Would you like to talk to a counsellor ... ?

Provide a clear action plan.

Your next appointment is If you feel pain or see skin redness ... [explain particular symptoms in a multisensory manner], get in touch with your therapist Or, ...

If you do not feel any changes in your symptoms despite doing ... [the suggested management strategies], keep in mind that it can take ... to show any benefits.

Products and systems should be designed in a way that minimises their perception as medical devices. These should be as discreet as possible.

Experimental

I explore new ways to manage better. It's a trial and error. I'm not totally confident about managing fluctuations.



I feel guilty if I don't manage my condition. I'm doing these because I'm afraid of the consequences.



I strictly follow what I was told.
- or -
I try them out.



I know my condition is permanent, but I still get upset when my symptoms increase.



I'm looking for ways to hide my condition, even if that limits me.



I was given information and received tools for self-management.



Design for Experimental Stage

SKILL-DEVELOPMENT FOR PROACTIVE PROBLEM SOLVING

Encourage learning new management strategies and expanding the self-management regime gradually. Encourage observing possible everyday-triggers.

How was it for you to manage your lymphoedema? Did you notice ... ? [Encourage reflections and observation of possible everyday triggers]. Did you try ... ? [introduce new management strategies and encourage active experimentation]

SELF-MONITORING FOR WELL-INFORMED DECISION MAKING

Encourage developing awareness of the symptoms and possible on-sets of fluctuations.

How is your arm/leg feeling? Does this ... [symptom] change when you ... ? [Encourage primarily subjective self-monitoring]

If there is interest for objective self-monitoring, facilitate that for understanding of 1) when professional help should be sought, 2) the effectiveness of self-management strategies, 3) how to adapt these strategies when needed, 4) the influence of possible triggers and out-of-routine activities.

Would you like to keep a record of these [symptoms] ... , which might help you to ... [adapt your management when needed] ... etc.

PERSONALISED GOALS FOR INTEGRATED HABITS

Understand personal goals and current habits. Suggest an everyday plan to achieve personal goals and to gradually broaden daily routines by experimentation:

*What would you like to achieve by self-management? [Understand personal goals and attitudes].
How do you manage your lymphoedema? Would you like to try ... [additional management strategies] for ... [patient driven objectives] ... , this can help you by ... [link to why that strategy is beneficial].*

Understand out-of-routine occasions.

How do you manage your lymphoedema during holidays ... [Understand possible out-of-routine occasions]

COLLABORATION FOR WELLBEING AND ADAPTATION

Encourage engaging with other people with lymphoedema, face-to-face and online. Encourage expressing personal lymphoedema stories to support the construction of identity with lymphoedema.

Would you like to have a chat with others living with lymphoedema? There is a group in your area. What do you think about ... [a management strategy or possible triggers] ... [sharing experiences with others].

Understand personal aspirations and goals for self-management. Develop an action plan together.

What would you like to achieve? How may I help you to build a self-management plan that works for you? How do you feel about lymphoedema? What is your aim until our next session? Would you like to talk about... [the new management strategy] and how that influenced your lymphoedema [encourage reflective observations].

Empowered

I can manage despite fluctuations.

I always look for new strategies to manage better.



I'm managing my condition because it's important for me, it corresponds to my goals and is a part of my life.



Self-management is a part of my everyday life. I adapted my everyday life.

- or -

I adapted my self-management to integrate it to my everyday life. I don't let my condition to take over my life.



I get on with my life as normal as possible.

- or -

I accept my condition. Thanks to my self-management, I can live the life I cherish.



I don't limit my life because of my condition. I don't let my condition identify me.

- or -

My condition is a part of my identity. I prioritise managing my condition and want others to learn about it.



I feel supported. We work in collaboration with my health-care professionals to better manage my condition.



Design for Empowered Stage

SKILL-DEVELOPMENT FOR PROACTIVE PROBLEM-SOLVING

Encourage staying up-to-date about new developments.

Did you try this new ... ? [Refresh information about management strategies and possible triggers].

Have you seen this new development ...? [Encourage the use of alternative sources of information including forums, blogs and social media]

SELF-MONITORING FOR WELL-INFORMED DECISION-MAKING

Encourage ongoing self-monitoring to be able to recognize when strategies are not as effective, when there are changes in circumstances and during out-of-routine activities.

How does your arm/leg feel when you ...? Would you like to try...? [new management strategies]?

PERSONALISED GOALS FOR INTEGRATED HABITS

Understand and support current self-management habits and personal goals. Refresh information about management strategies and possible triggers.

How do you manage your lymphoedema? What do you think successful self-management is? Did you try this new ...?

COLLABORATION FOR WELLBEING AND ADAPTATION

Encourage engaging with other people with lymphoedema, face-to-face and online. Encourage expressing personal lymphoedema stories to support the construction of identity with lymphoedema.

Would you like to have a chat with others living with lymphoedema? There is a group in your area.

What do you think about ... [a management strategy or possible triggers] ... [sharing experiences with others].

Understand personal aspirations and goals for self-management. Develop an action plan together.

What would you like to achieve? How may I help you to build a self-management plan that works for you? How do you feel about lymphoedema? What is your aim until our next session? Would you like to talk about... [the new management strategy] and how that influenced your lymphoedema [encourage reflective observations].

Products and systems could be designed to look more conspicuous to start conversations and to spread the word about lymphoedema.