

# Design for Multi-Dimensional Stages of Lymphoedema Self-Management

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doi: 10.21606/dma.2017.549

This study investigates the experience of people with the chronic medical condition lymphoedema, to inform the design of new products. Articles from literature that describe lived lymphoedema experiences are thematically synthesised from a behavioural lens. People with lymphoedema go through stages toward achieving levels of expertise, motivation and routine, to maintain effective self-management in the long-term. A preliminary framework is proposed that presents four themes (competence, autonomy, daily routine and socio-psychological) and their stages. The purpose of the framework is to assist designers in understanding how people with lymphoedema experience self-management. Focusing on facilitating a transition through these multi-dimensional stages is suggested as a means to aid the design of supportive health products. Related design implementations are discussed through product examples. This framework is developed as part of a wider research project, where the following stages will be concerned with refinement of the framework through primary research with people with lymphoedema and their healthcare providers.

*design for self-management; lymphoedema; chronic conditions; health and wellbeing*

## 1 Introduction

Lymphoedema is a chronic swelling caused by the failure of the lymphatic system. The swelling can occur in any part of the body, but usually affects arms or legs. Symptoms are heaviness, pain, stiffness, numbness, poor range of motion and acute infections. It can be encountered at any age due to congenital abnormality or after cancer therapy, cellulitis and trauma. The prevalence of lymphoedema is increasing; it has been reported that five out of every 1000 people in Wales have the condition (M. J. Thomas & Morgan, 2017).

This paper is an initial part of a doctoral study and aims to inform primary research in preparation to co-design self-management support systems, with the active involvement of people with lymphoedema and their healthcare providers. Findings of the literature review describing the



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transition to self-management that people with lymphoedema experience is presented with related design implementations.

Self-management implies a shift of care from clinic to home. This transition benefits healthcare systems by decreasing the number of clinical visits, and people with lymphoedema by diminishing the impact it has on their lifestyle. Unlike an acute illness, patients with chronic conditions make day-to-day decisions about how they manage their health for the rest of their life (Anderson & Funnell, 2000). They control levels of adherence with prescribed tasks necessary to managing their condition. According to the World Health Organisation, nearly fifty percent of people with chronic diseases have poor adherence to their treatment (Sabaté, 2003). From a patient's perspective, adherence to treatment requires additional daily tasks and a change in behaviour, which needs medical, social and emotional support (Corbin & Strauss, 1985; Dwarswaard, Bakker, Staa, & Boeije, 2016). Design has an important role in addressing those support needs and promoting healthy behaviour (Tseklevs & Cooper, 2017). Appropriate design can improve behavioural and clinical outcomes (Balaam et al., 2011; Moffatt & Murray, 2010; Nunes et al., 2015; Sawesi, Rashrash, Phalakornkule, Carpenter, & Jones, 2016), however, the everyday support needs of people with lymphoedema is rarely investigated in this context (Chamberlain, Wolstenholme, & Dexter, 2015; Galiano-Castillo et al., 2014).

Gaining insights about the lived experiences of people with lymphoedema is fundamental for designing support products and systems that aim to facilitate self-management. The benefits of User-Centred design approaches at eliciting the active participation of patients and clinicians for developing healthcare products are acknowledged (Bate & Robert, 2006; McCarthy et al., 2016; Pickles, Hide, & Maher, 2008). This paper aims to describe the experience of people with lymphoedema towards effective self-management, and discuss possible approaches to design for assisting people in this transition.

## **2 Background**

### **2.1 *Lymphoedema Self-Management***

The mainstream care of lymphoedema follows a Complete Decongestive Therapy (CDT), which consists of two phases: reduction and self-management. The reduction phase is an intensive daily procedure of lymphatic massage, compression bandaging and skin care carried out by a lymphoedema therapist three times a week for around 3-8 weeks. After the success of the reduction phase, people with lymphoedema are responsible for carrying out these laborious activities by themselves for the rest of their life; by wearing compression garments, doing massage and skin care as well as being cautious about injuries and signs of infections. People who wear prescribed compression garments and exercise experience less pain; however, nearly half of the people continue bearing some symptoms and face at least one infection episode after their diagnosis (Deng et al., 2015). Many people with lymphoedema do not consider selectively applying the prescribed tasks as non-adherence "but as a strategy of making the changes in their lives feasible" (Fu, 2005, p. 455). Hence, it is critical to understand everyday self-management strategies of individuals and how they have developed those in order to design for them.

### **2.2 *Design for Supporting Self-Management***

User-Centred Design approaches prioritise the voices of the end users during the whole design process to design products that people actually need, want to buy, can use and want to use in the long term. Participatory design and co-design methodologies present opportunities for designers to engage with people/users during the design process. In healthcare, patient involvement in design is highly valuable, since specific symptoms of medical conditions and the variety of health journeys make it even more challenging to empathize. Various User-Centred approaches have been implemented in healthcare to address those challenges (Balaam et al., 2011; Bate & Robert, 2006; McCarthy et al., 2016; Pickles et al., 2008). Still, it is discussed that failing to utilise well-established

behavioural theories of psychology limit the effectiveness of healthcare products and services (Nunes et al., 2015; Riley et al., 2011; Sawesi et al., 2016). There is a call for systematically eliciting dynamic and diverse needs of patients while effectively employing health behaviour theories (Chiauzzi, Rodarte, & DasMahapatra, 2015; Kanstrup, 2014; Nunes et al., 2015). Moreover, new approaches are needed to make that information feasible to design applications. Even though multidisciplinary literature provides in-depth qualitative studies describing the experience of people with chronic conditions, it is not presented in a way that provides insights for design purposes. This paper synthesises the literature of the experience of people with lymphoedema and related behaviour change models, to present guidance for designers.

### 3 Development of the Framework

In preparation for qualitative studies with lymphoedema patients, a broad literature review was undertaken exploring studies related to chronic conditions and self-management, related products and technologies, design approaches, and behavioural theories. From this, two focussed bodies of literature were further investigated: literature that describes experiences of people with lymphoedema; and, behaviour change theories. The purpose of this more focussed review was to extract a better understanding of the needs of patients.

A wide range of qualitative studies were reviewed; arising from this review, 10 articles were purposefully selected that presented in-depth descriptions of the lived experience of adults with lymphoedema (see table 1). These articles are thematically synthesised following three stages as discussed by J. Thomas and Harden (2008). First, the findings of reviewed articles were analysed and clusters were named, and then those were organised to create descriptive themes. During the final phase of the thematic synthesis, the themes were interpreted through our research question: How do people with lymphoedema experience the transition towards effective self-management?

*Table 1 List of the thematically synthesised articles about the lymphoedema experience.*

|    | Reference                                | Number          | Lymphoedema Type                                     | Data Collection Method / Data Analysis Approach                       | Country   |
|----|--|-----------------|--|---|-----------|
| 1  | Ridner et al., 2016                      | 21 women        | Breast Cancer Related Lymphoedema (BCRL)             | Focus group interviews / Qualitative Descriptive                      | USA       |
| 2  | Jeffs et al., 2016                       | 21 women        | BCRL   | In-depth interviews / Grounded Theory                                 | UK        |
| 3  | Barlow et al., 2014                      | 14 women        | BCRL   | Semi-structured and focus groups interviews / Qualitative Descriptive | UK        |
| 4  | Meiklejohn, Heesch, Janda, & Hayes, 2013 | 3 men, 26 women | Lymphoedema after cancer therapy                     | Focus group and telephone interviews / Contents Analysis              | Australia |
| 5  | Ridner, Bonner, Deng, & Sinclair, 2012   | 39 women        | BCRL   | Writings at home for two weeks / Qualitative Descriptive              | USA       |
| 6  | Fu, 2010                                 | 34 women        | BCRL   | In-depth interviews / Descriptive Phenomenological                    | USA       |
| 7  | Bogan et al. 2007                        | 3 men, 4 women  | Non-cancer-related lymphoedema                       | Semi-structured interviews / Qualitative Descriptive                  | USA       |
| 8  | Greenslade & House, 2006                 | 13 women        | BCRL   | Semi-structured interviews / Phenomenological                         | Canada    |
| 9  | Thomas-MacLean, et al. 2005              | 22 women        | BCRL   | Semi-structured and focus group interviews / Not mentioned            | Canada    |
| 10 | (Williams, Moffatt, & Franks, 2004)      | 15 men & women  | Lymphoedema both after cancer and non-cancer related | Phenomenological Interviews / Phenomenological                        | UK        |

Themes about gaining control, expertise and habits emerged, showing various levels towards self-management goals. To understand the constructs of these descriptive themes, behavioural theories were investigated. The correlation between the findings of this review and behavioural theories enabled the synthesis of four main themes and their related stages: competence, autonomy, daily routine and socio-psychological.

A dominant aspect identified is the dynamism of those themes; people with lymphoedema are explicitly aware of the various phases they are going through. This is illustrated in the case of one person interviewed as part of the thematic synthesis, who stated that “I suppose it’s like a grieving process, you’ve got to go through different stages” (Meiklejohn et al., 2013, p. 6). The subthemes of competence, autonomy and daily routine revealed several stages people experience while they are adjusting to life with lymphoedema. The last theme encompasses the socio-psychological aspects which is structured around main influential actors.

Four themes are discussed in the following sections: 3.1) Competence: Novice to Expert, 3.2) Autonomy: External to Intrinsic Motivation, 3.3) Everyday Routine: Intention to Action, 3.4) Socio-psychological. Each theme is elaborated around lived experiences of people with lymphoedema in relation to aspects of behavioural theories, and related design implementations are discussed.

### 3.1 Competence: Novice to Expert

People need to think that they can successfully perform the recommended self-management task, in order to consider doing it. Perceived confidence as a prerequisite for behaviour, is mentioned as “competence” by Ryan and Deci (2000) and “self-efficacy” by Bandura (1977).

Even though diagnosis of the condition is primary, some people had to cope with lymphoedema without knowing for extended periods (Bogan et al., 2007; Williams et al., 2004) and some diagnosed themselves from online sources (Barlow et al., 2014; Ridner et al., 2016). After diagnoses, the lack of information and support is still the main source of frustration for many people with the condition (Barlow et al., 2014; Fu, 2010; Greenslade & House, 2006; Ridner et al., 2016; Thomas-MacLean et al., 2005; Williams et al., 2004).

Dreyfus and Dreyfus (1980)’s “Skill Acquisition Theory” describes skill levels and emphasises the importance of established cases and experience for learning new skills. Their four skill levels are adapted to describe how people with lymphoedema gain competence and build expertise (Figure 1). Their fifth level is called “mastery” and described as being absorbed in the activity. That was excluded, since no such evidence was found in the literature review for lymphoedema self-management.

## Competence



Figure 1 Competence and related design implementations. Skill Acquisition levels adapted from Dreyfus and Dreyfus (1980)

**Novices** know rules but cannot correlate those with specific situations (Dreyfus & Dreyfus, 1980). This is reflected in lymphoedema when an individual first learns about self-management tasks, but does not know how to integrate them to daily life and their practical effects to their symptoms (Fu, 2010; Greenslade & House, 2006; Jeffs et al., 2016; Meiklejohn et al., 2013; Ridner et al., 2012; Williams et al., 2004). A study exploring lymphoedema self-management education in the USA presented that, even though people receive education about lymphoedema, around 30% do not find it adequate for themselves (Ridner, Dietrich, & Kidd, 2011).

*I'm more practical. I prefer someone to show me, and she [lymphoedema therapist] has shown me but only once and I can't, I didn't take it in. (Jefferis et al., 2016, p. 5)*

**Competence** is acquired with experience or when the context of the rules are provided with real world examples (Dreyfus & Dreyfus, 1980). After the initiation of the behaviour, people's competence is highly affected by their experience of success and failure. Bandura (1977) names this "performance accomplishments". Being aware of the possible consequences of not doing self-management is a major motivator for many people (Bogan et al., 2007; Jefferis et al., 2016; Williams et al., 2004), still some choose not manage their lymphoedema despite knowing its impact to their swelling (Fu, 2010; Jefferis et al., 2016; Ridner et al., 2012). People with lymphoedema mention how they start to feel the benefits of self-management (Bogan et al., 2007; Jefferis et al., 2016), however, it is a long-term investment and not feeling the benefits right-away can be a barrier for some (Jefferis et al., 2016; Ridner et al., 2012).

**Proficiency** comes with experience in a variety of situations (Dreyfus & Dreyfus, 1980). People with lymphoedema express how they develop ways to plan their self-management for changing situations such as flights, holidays and days that require overusing the affected limb (Ridner et al., 2016; Williams et al., 2004). Acknowledging the effects of various self-management aspects to individual symptoms by experience, provides people the competence to adapt and alter those occasionally (Fu, 2010; Jefferis et al., 2016).

People with lymphoedema assess their swelling by "size, appearance, internal sensations, and the feel or consistency of their swollen limb" (Jefferis et al., 2016, p. 8). Healthcare providers measure the limbs to compare with their previous notes as well as carrying out a subjective assessment. Measurable characteristics of chronic conditions are mostly preferred in clinic because of their ability to provide objective comparisons. Some people with lymphoedema want to be measured by nurses (Williams et al., 2004), "I may not notice it, but a tape measure would." (Jefferis et al., 2016, p. 6). Still, the subjective measures and sensations can be different compared to the objective measurements:

*When I've come and told the nurse here I think my arm is quite swollen she measures it up ... and will say, 'Oh, it's only about 30 or 50 mls difference in volume.'...if you measure it in a glass of water, [that] is pretty small ... but the impact I think is way more than what the volume states. (Jefferis et al., 2016, p. 8)*

**Expertise** is gained when people can intuitively make decisions without conscious thinking (Dreyfus & Dreyfus, 1980). In lymphoedema, being an expert is expressed in relation to having a daily routine, taking control and feeling competent about controlling the fluctuations of their swelling (Barlow et al., 2014; Jefferis et al., 2016; Meiklejohn et al., 2013; Ridner et al., 2016).

Design implementations for assisting the transition towards "expertise" are discussed in the next sections.

### **3.1.1 Skill Development**

It is shown that education programmes focusing on self-management skills are better at improving clinical outcomes compared to programmes providing only information (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Utilising online platforms for the dissemination of information is common and opportunities arise for facilitating skill development. For instance, Lymphoedema Network Wales e-mails evidence-based videos made by patients as a part of their patient education (Thomas & Morgan, 2017). Fu et al. (2016) developed a web-based system for women after breast cancer therapy. Their system starts with providing tools to let people evaluate their lymphoedema symptoms and delivers daily strategies for having optimal lymphatic flow (Fu et al., 2016).

### **3.1.2 Self-Monitoring**

Experiencing the consequences and benefits of self-management increases the motivation as mentioned frequently by people with lymphoedema (Barlow et al., 2014; Bogan et al., 2007; Jefferis et

al., 2016; Williams et al., 2004). Kikuhime Telecare System (McLaren, Helmer, Horne, & Blanchonette, 2010) uses sensors placed under bandages for measuring compression continuously. Li et al. (2016) developed an ultra-thin and flexible sensing system that can be worn with compression garments without adding extra thickness. These two devices provide information about the compression to the wearer and the therapist. Measuring the limb circumference from defined sections is the common method used by lymphoedema specialists to follow swelling progress. For some people those measurements are very critical and their main reason to see their specialists (Jefferies et al., 2016). E-Cuidate is a software that enables people to log measurements manually and share these with their therapists (Galiano-Castillo et al., 2014). Another approach is measuring the circumference continuously by a sensor embedded cuff (Fallahzadeh et al., 2015).

### 3.2 **Autonomy: External to Intrinsic Motivation**

Autonomy is defined as an individual’s perception about their volition in giving decisions and being in control. Anderson and Funnell (2000) emphasise the importance of autonomy in self-management of chronic conditions by “It’s not that people are unwilling to change, it’s that people are unwilling to be changed” (p. 603). According to Ryan and Deci (2000), autonomy together with competence and relatedness are the prerequisites of motivation. Ryan and Deci (2000)’s Self-Determination continuum is adapted to explain how people with lymphoedema ultimately identify self-management as critical for themselves and integrate it into their everyday life (Figure 2). Their final stage called “intrinsic motivation” (Ryan & Deci, 2000) was not included, since lymphoedema self-management tasks are not naturally interesting or delighting.

## Autonomy

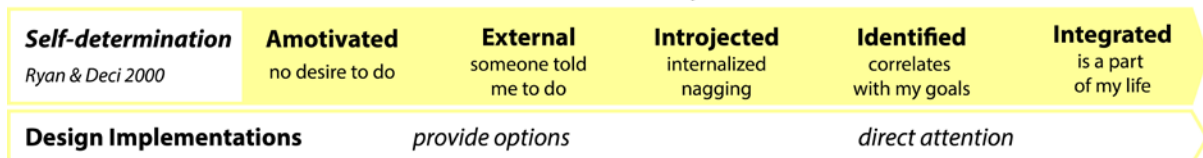


Figure 2 Autonomy and related design implementations. Types of motivations are adapted from Ryan and Deci (2000)

**Amotivation** can be a result of not expecting or giving value to the outcome, or not feeling competent for achievement (Ryan & Deci, 2000). One study shows that 20% of the participants do not believe they can make a difference in their lymphoedema by what they do (Ridner et al., 2011).

*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. 7)*

Corresponding to **external** motivation concept of Ryan and Deci (2000), some people mention aspects of self-management as something that was told to them, and explain how they tried doing it, but cannot continue in the long term (Fu, 2010; Jefferies et al., 2016).

*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, p. 8)*

**Introjected** motivation is defined as feeling guilty about not doing something (Ryan & Deci, 2000), which is expressed by women as feeling bad (Fu, 2010) and faulty (Greenslade & House, 2006) about not self-managing properly.

People who perform activities because they value its goal and outcome are holding **identified** motivation (Ryan & Deci, 2000). People with lymphoedema frequently identify the consequences of not doing self-management as their main motivation (Bogan et al., 2007; Jefferies et al., 2016). The fear of results of not self-managing is even more dominant for the ones who experienced severe symptoms because of late diagnosis (Bogan et al., 2007).

*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. 5)*

By building habits and routines around their self-management activities, people with lymphoedema build **integrated** motivation (Barlow et al., 2014; Bogan et al., 2007; Fu, 2010; Jefferis et al., 2016; Meiklejohn et al., 2013; Williams et al., 2004).

Design implementations for assisting the transition towards integrated motivation are discussed in the following sections.

### **3.2.1 Provide Options**

Ammerlaan et al. (2016) designed a web-based self-management intervention, and discuss the need to address autonomy by letting people choose from various educational modules according to their personal goals. Similarly, drawing a “possibility tree” to provide options and explain different routes to accomplish different goals is suggested as a design strategy (Lockton, Harrison, & Stanton, 2010).

### **3.2.2 Direct Attention**

Designing to increase autonomy implies transforming the role of design from designing to motivate people, to designing for enabling people to be motivated by themselves (Bisset & Lockton, 2010). Interventions that are “nudging” people by sending notifications for changing their health behaviour, are criticised to be leading the decisions and keeping their users passive (Schüll, 2016), hence hindering autonomy. Niedderer (2013) discusses that design can be utilised to stimulate one’s mindful awareness by “shifting the focus from an external to an internal locus of control” (p. 4567). Similarly, “nakedness” is a tool described by Lockton et al. (2010) as removing the elements that people are taking for granted to make them more aware of their surroundings.

People with lymphoedema express their constant consciousness of pain and swelling (Barlow et al., 2014; Greenslade & House, 2006; Meiklejohn et al., 2013; Thomas-MacLean et al., 2005), designing to refocus attention from negative situations is suggested as a design strategy (Casais, Mugge, & Desmet, 2016).

## **3.3 Everyday Routine: “Intention to Action”**

During the clinical therapy of lymphoedema (reduction phase of the CDT), people cannot drive or take a shower when the bandages are on and usually cannot continue their regular work routines. The constraints of having bulky bandages is frustrating, still some people are more anxious about coming to the end of the therapy and coping with it at home without therapist assistance (Ridner et al., 2016; Williams et al., 2004). Unlike clinical therapy, people at home cannot access the encouragement and aid clinicians provide. People should make a volitional choice for self-management and create time while keeping up with their other responsibilities, which is quite different from attending an appointment in a clinic.

Intention is a prerequisite of behaviour (Ajzen, 1985); still even people with positive intentions in self-management are observed to be unsuccessful in reflecting that to their behaviour (Berg, Evangelista, Carruthers, & Dunbar-Jacob, 2011). Webb and Sheeran (2006) investigate the links between intention and the actual behaviour, and they show the importance of volitional and habitual controls for describing the gap found between those. Triandis (1977) defines behaviour partly deliberate influenced from intentions and partly autonomic influenced from habits.

The stages of change model of DiClemente and Prochaska (1983) suggests five stages that people go through for sustaining a health behaviour change. During the first three stages, people build intention and prepare for change, while the last two is when they actually perform the new behaviour. Tang and Bhamra (2008), in their study about changing energy consumption behaviour, draw a sequence for building new habits. The stages of change (DiClemente & Prochaska, 1983) and the habit building process (Tang & Bhamra, 2008) are adapted to express the stages people with lymphoedema go through for building and maintaining self-management habits (Figure 3).

Some people with lymphoedema are attached to their old habits and express reluctance to change (Fu, 2010; Ridner et al., 2012)

*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. 8)*

## Daily Routine

| <b>Habit building</b><br><i>Tang &amp; Bhamra 2008</i>            | <b>Old habit</b>                         | <b>Awareness</b>                                  | <b>Consideration</b>                        | <b>Practice</b>                             | <b>Repeat</b>         | <b>New habit</b>                                    |
|---|--|---|---|---|-----------------------|---|
| <b>Stages of Change</b><br><i>Prochaska &amp; DiClemente 1983</i> | <b>Pre-C.</b><br>no intention for change | <b>Contemplation</b><br>considering future action | <b>Pre-action</b><br>have a plan for action | <b>Action</b><br>practice the new behaviour |                       | <b>Maintenance</b><br>keep performing the behaviour |
| <i>Ludden &amp; Hekkert 2014</i>                                  | <i>raising awareness</i>                 |   | <i>enabling</i>                             |   | <i>motivation</i>     | <i>fade-out</i>                                     |
| <b>Design Implementations</b>                                     |  | <i>planning and self-regulating</i>               |   |   | <i>habit building</i> |   |

Figure 3 Daily Routine and design implementations. Habit building stages adapted from Tang and Bhamra (2008), Stages of Change adapted from DiClemente and Prochaska (1983), and Stage-matched design strategies adapted from Ludden and Hekkert (2014)

Some people with lymphoedema have difficulty in taking action, even though they have awareness (Jeffs et al., 2016; Ridner et al., 2012), while some others take action, but fail to repeat those (Fu, 2010; Ridner et al., 2012)

*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, p. 9)*

For many other people, building a daily routine around self-management helps to lessen the effects of lymphoedema on their life, feel in control and gain normalcy; since they think less about it, but do more (Bogan et al., 2007; Jeffs et al., 2016; Meiklejohn et al., 2013; Williams et al., 2004).

*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, p. 3)*

Design implementations for assisting people to build and maintain a daily routine are discussed in the following sections.

### 3.3.1 Design for Stages of Change

As discussed earlier, the stages of change theory distinguishes different stages of readiness for change (DiClemente & Prochaska, 1983). Ludden and Hekkert (2014) draw into that theory and define stage-matched design strategies: "raising awareness, enabling, motivation and fading out". Raising awareness is suggested for people without intention to change and while they start to consider action. "Enabling" strategies are advised to make individuals, who consider change, to start performing the new behaviour. "Motivational" strategies are suggested to help people in maintaining the new behaviour (Ludden & Hekkert, 2014). It is discussed that designing for people at different stages of change, but not only the ones who are already motivated to change, enables designers to address a wider population (Karapanos, 2016).

The thematic synthesis presented in this paper suggests that people with lymphoedema go through stages not only in terms of their readiness for change, but also for building competence, autonomy and habits. The stages of change theory and stage-matched design strategies (DiClemente & Prochaska, 1983; Ludden & Hekkert, 2014) are adapted and incorporated within "daily routine" theme in parallel to habit building (Figure 3).



### 3.3.2 *Planning and Self-regulating*

When people make plans about accomplishing their goals, they are more inclined to perform those activities by volitional control. Interventions that help people to draw a personal programme (such as dairies, action planning and coping planning) suggested to be useful in increasing volition of people who are already motivated for change (Sniehotta et al., 2005). Setting challenges and targets are ways to support people in consciously identifying their goals (Lockton et al., 2010; Michie et al., 2013).

### 3.3.3 *Habit Building*

Habits are automatic actions as a response to cues, developed by consistent repetitions (Lally & Gardner, 2013). Fogg (2009) underline the importance of “triggers” to tell people, who are already motivated and capable of, to perform an action at a specific time. After performing an already existing routine, adding a new small behaviour and gradually increasing that action is suggested for creating new habits (Fogg, 2009).

Lally and Gardner (2013) discuss satisfaction with the new behaviour as being critical for the consistent repetition required to build habits. People with lymphoedema have different opinions about the definition of success in self-management; some people believe that they are successful if their swelling does not increase, while for others that means poor progress (Jefferis et al., 2016). Setting realistic expectations and emphasising the importance of undervalued outcomes are suggested for promoting habits as well as providing cues and feedback (Lally & Gardner, 2013).

## 3.4 *Socio-psychological*

The social and psychological aspects of chronic conditions discussed to be usually neglected (Corbin & Strauss, 1985; Dwarswaard, Bakker, Staa, & Boeije, 2016; Lorig & Holman, 2003). The literature demonstrates the importance of four main actors for people with lymphoedema: family & friends, healthcare providers, peer patients and other people around. Socio-psychological aspects are organised in relation to those actors (Figure 4).

Some people with lymphoedema say that they cannot access any help because of being alone, or they feel their needs are not understood within their family (Fu, 2010; Ridner et al., 2012; Ridner et al., 2016). Having supportive **family and friends** around, provides physical support, such as help in wrapping the effected limb as well as emotional support. People with lymphoedema express how they change the way they do chores at home according to their changing capabilities or had to ask for help (Bogan et al., 2007; Fu, 2010; Greenslade & House, 2006; Ridner et al., 2016; Thomas-MacLean et al., 2005). Some people express their reluctance to ask for help because of their concerns about being a burden to them or losing their independence (Ridner et al., 2012; Ridner et al., 2016).

*...it just makes you feel as though you can do things.....instead of having somebody else to do them for you...and it just makes you feel more useful to yourself.. (Barlow et al., 2014, p. 11)*

Collaboration between **healthcare providers** and patients is critical for effective self-management support (Anderson & Funnell, 2000; van Hooft, Dwarswaard, Jedeloo, Bal, & van Staa, 2015). Some people with lymphoedema express how building a strong relationship with their lymphoedema therapists helped them (Barlow et al., 2014; Bogan et al., 2007; Williams et al., 2004).

*...they [lymphoedema therapists] said they can't cure me but they will keep it under control and that is precisely what they did...I think I began to have some confidence when I could see that what they were doing was working and I became more confident again. (Barlow et al., 2014, p. 10)*

People compare lymphoedema with other chronic conditions and cancer; and express their frustration about underestimation of their needs, not having similar privileges and empathy from healthcare providers (Barlow et al., 2014; Bogan et al., 2007; Greenslade & House, 2006; Ridner et al., 2012; Ridner et al., 2016; Williams et al., 2004).

*...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 & House, 2006, p. 168)*

Dwarswaard et al. (2016)'s review on chronic conditions shows that **peer support** is beneficial by presenting success stories, normalising living with it and decreasing related anxiety. Learning from the experience of others, termed 'vicarious experience', is one of the sources of self-efficacy (Bandura, 1977). People with lymphoedema express their desire to share their experience to help others (Bogan et al., 2007; Ridner et al., 2012), as well as the support they get from connecting with peer patients (Barlow et al., 2014; Jeffs et al., 2016; Meiklejohn et al., 2013).

*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, p. 219)*

| ACTORS               | Socio-Psychological | GOALS                | Design Implementations  |
|----------------------|---------------------|----------------------|-------------------------|
| Family and Friends   |                     | <b>Independence</b>  | telehealth              |
| Healthcare Providers |                     | <b>Support</b>       | facilitate peer support |
| Peers                |                     | <b>Connectedness</b> | tailored representation |
| Others               |                     | <b>Acceptance</b>    |                         |

Figure 4 Socio-psychological aspects of lymphoedema self-management and related design implementations

Goffman (1959) explains how people choose to present themselves to **other people** around with a theatre stage metaphor: the impression created on others is guided by changing the way the individual looks and acts in the front stage of the theatre, while relaxed in the backstage. Hence, people control who can access their backstage and may misrepresent themselves to the others in order to fit in their "ideals" (Goffman, 1959).

Some people with lymphoedema think that their swelling does not fit to their ideal and want to hide their condition from others (Bogan et al., 2007; Fu, 2010; Greenslade & House, 2006; Jeffs et al., 2016; Ridner et al., 2012). One talks about her frustration about bandages: "You can't hide it when it's bandaged like this, it's in your face quite literally" (Williams et al., 2004, p. 284). Compression garments are also perceived as increasing the visibility of the swelling, which is a further barrier to wearing them (Barlow et al., 2014; Jeffs et al., 2016; Ridner et al., 2012).

*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, p. 8)*

Finding clothes and shoes to accommodate, and hide the swollen limb is a frustration (Bogan et al., 2007; Greenslade & House, 2006; Ridner et al., 2012), and when the swelling cannot be hidden, the reactions of other people to the affected limb can cause emotional breakdowns (Bogan et al., 2007; Williams et al., 2004). The idealised-self is expressed as "being normal" by many (Bogan et al., 2007; Greenslade & House, 2006; Jeffs et al., 2016; Meiklejohn et al., 2013; Ridner et al., 2012), while the route to normal life is suggested to be effective management of the condition (Bogan et al., 2007). Some people express how acceptance of having lymphoedema for the rest of life helped them gain control (Bogan et al., 2007; Jeffs et al., 2016; Ridner et al., 2012).

*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, p. 5)*

Design implementations for the socio-psychological aspects are discussed in the following sections.

### 3.4.1 *Telehealth*

During face-to-face clinical assessments, lymphoedema specialists measure arm circumferences to evaluate the differences between two arms as well as keeping track of the progress. Galiano-Castillo et al. (2014) design and assess a telerehabilitation system to monitor arm measurements of breast cancer survivors. A telehealth system is utilised with the help of a caregiver to measure and log circumferences, while talking with the specialist is enabled via videoconference. The measurements were compared between face-to-face and telerehabilitation system and found to be reliable (Galiano-Castillo et al., 2014). Another telehealth application aiming to teach self-management to people with chronic swelling with mobility problems is well rated by participants (Faett, Brienza, Geyer, & Hoffman, 2013).

### 3.4.2 *Facilitate Peer Support*

Peer support is discussed to be a critical aspect of social and psychological support (Dwarswaard et al., 2016). The importance of building equality and mutual understanding between peers is emphasised for design implementations (Embuldeniya et al., 2013). Local lymphoedema support groups facilitate peer support and many people share their stories through social media.

### 3.4.3 *Tailored Representation*

Even if a product is beneficial and necessary in medical terms, people can be reluctant to use a feature if perceived to be stigmatising and not aesthetically pleasing (Wilkinson & De Angeli, 2014). Presentation of Self Theory (Goffman, 1959) discusses how people represent themselves in society. Consolvo, McDonald, and Landay (2009) considered the implementation of that theory in the design of a physical activity display. They emphasised the importance of aesthetics and the ability to control the outputs by its users if misrepresentation is desired (Consolvo et al., 2009). In the context of Lymphoedema, the look of compression garments and how people react to those is a frequently mentioned barrier (Barlow et al., 2014; Jeffs et al., 2016; Ridner et al., 2012). Sleeves with tattoo metaphors (Ercolano, 2012) have been demonstrated to be successful in changing the medical look of the compression garments and in facilitating individualisation. Another example of this is the purse that integrates an arm sling, to both help support the affected arm as well as camouflaging it in a fashionable way (Barnwell, Tullio-Pow, & Nyhof-Young, 2009).

## 4 **Conclusion**

A shift of care from clinics to homes are increasingly encouraged and necessary for many chronic conditions, including lymphoedema being the focus of this paper. The transition experienced towards effectively self-managing at home is discussed through a literature review of lymphoedema, behavioural theories, design approaches, studies related to chronic conditions and self-management. From the thematic synthesis of ten articles expressing the lived experiences of people with lymphoedema, multi-dimensional stages are distinguished, which are illustrated as a new preliminary framework in Figure 5. While some individuals proceed through those challenging stages, others fall behind in some aspects resulting in barriers to self-management. This understanding is important to facilitate the successful transition of people at the beginning of such periods and for the ones facing difficulties.

Obviously, this review has limitations in understanding the lived-experience of managing lymphoedema. Primarily, the thematic synthesis has been developed through secondary research, which prevents an in-depth understanding of the design needs of any new product. Seven of the ten articles reviewed in this study focussed on people with lymphoedema after breast cancer therapy, since the literature is limited for other types of lymphoedema. Yet, despite these limitations, the review has presented an opportunity to include the experiences of people from different parts of the world: USA, Canada, Australia and UK. The outcome describes the multi-dimensional stages people with lymphoedema go through for self-management. Future work will include a systematic literature review, and primary data collection by interviews and co-design workshops. Self-

management is a critical component of care not only for lymphoedema, but also for other chronic conditions. Themes specific to other chronic conditions would be revealed by future investigations.

Guidance for design is provided by discussing design approaches in relation to how to assist the transition from clinical treatment to effective self-management. Ten design implementations matching those specific themes are identified, and discussed with relevant product examples. This preliminary framework presents the great variety of lived self-management experiences, and the inadequacy of one-design-fits-all approaches. Not only the impact of lymphoedema and strategies to manage are different for individuals but also each day is different in this respect. Focusing on these multidimensional factors by considering their stages and ultimate goals, would allow designers to better understand and address the opportunities to alleviate self-management.

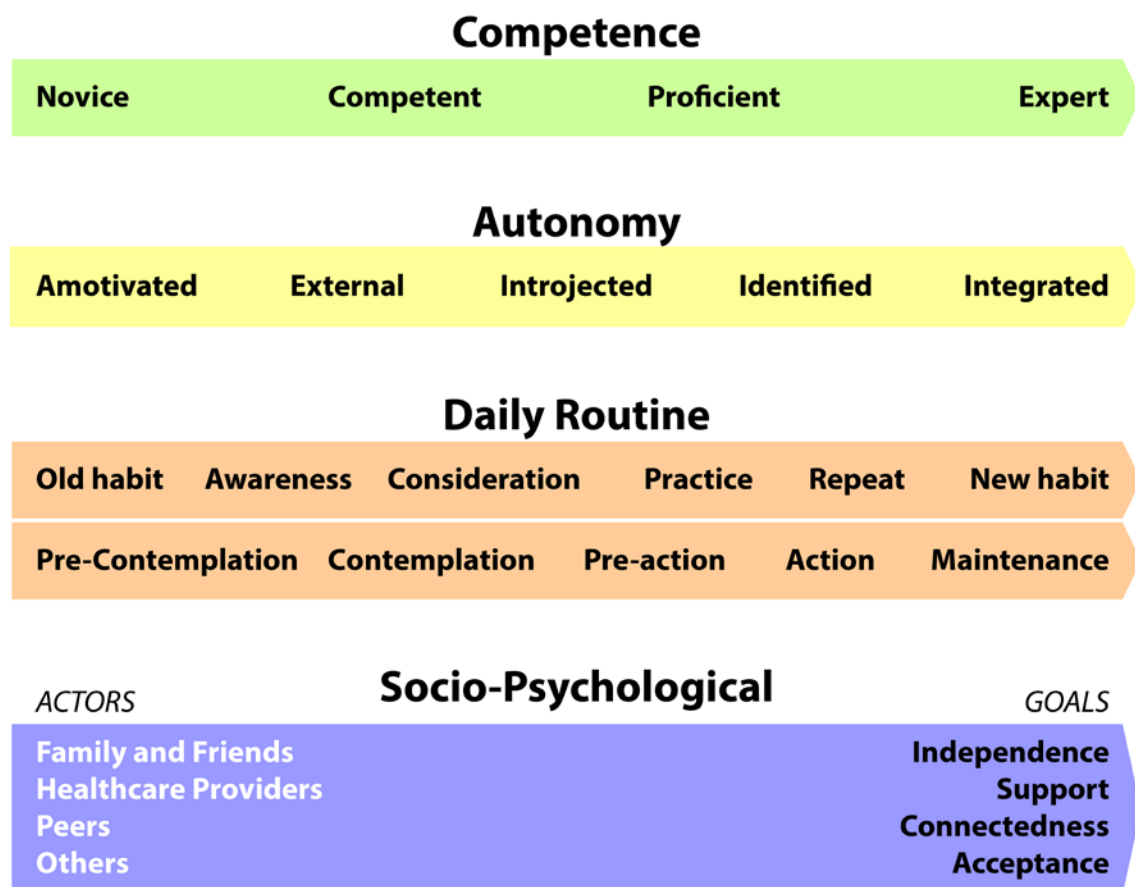


Figure 5 Multi-dimensional stages of lymphoedema self-management experience

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