

Uncovering Self-management Needs to Better Design for People Living with Lymphoedema

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This paper reports on the application of design-based tools used to uncover the needs of people living with a chronic condition. It was built on increasing rhetoric calling for greater involvement of patients in the creation of appropriate support mechanisms, and presents a means to achieve this using design approaches and tools. The paper presents the development and use of scenario-based design probes to facilitate participation of People Living with Lymphoedema (PLWL) early in the design process. Lymphoedema is a chronic condition requiring a cumbersome everyday management routine. Self-management support is necessary to increase quality of life, and decrease complications and hospitalisation. However, consistent practice of self-management among PLWL is low and the need to improve support is recognised. This research explored how PLWL's transitions towards becoming experts of their condition might be supported. Literature describing the lymphoedema experience was systematically investigated from a behavioural perspective to develop scenario-based probes. These probes provided rich insights by facilitating the envisioning of alternative futures to self-management support with interview participants with lymphoedema. To inform the design of better support for chronic conditions, the stages and components of behaviour change for lymphoedema self-management, and the associated support needs are presented.

Keywords: self-management; lymphoedema; chronic conditions; user-centred design; scenario-based design probes

Introduction

The research presented in this paper is a part of a larger project which uses design to improve the way the medical condition, lymphoedema is managed.

Lymphoedema is a progressive and chronic swelling of a part of the body caused by the excessive accumulation of lymphatic fluid in the tissues. It can present in any part of the body, but usually occurs in arm(s) or leg(s). Symptoms include swelling, heaviness, pain and increased susceptibility to cellulitis. There are two types of lymphoedema: primary, a genetic condition that could develop at any age, and secondary, caused by damage to the lymphatic system from injury, infection or, most commonly, cancer treatment. It is estimated to affect more than 120 million people worldwide (Moffatt et al. 2012).

Lymphoedema is not currently curable, but its progression and complications can be managed (Grada and Phillips 2017). If needed in severe cases, an intense clinical treatment can be applied to reduce the swelling. Whether or not clinical therapy is carried out, PLWL should practice self-management strategies every day which include: wearing compression garments; skin care regimes; exercises; and massages (Lymphoedema Framework 2006). Lymphoedema self-management implies gaining specific skills, making behavioural changes and undertaking burdensome routines. Poor management of lymphoedema may result in recurrent clinical treatments, increased swelling, poor quality of life and increased likelihood of complications such as cellulitis. However, Ridner et al. (2011) showed that consistent practice of self-management among PLWL was low.

Care for people with chronic medical conditions has been estimated to constitute around 70% of the healthcare costs in England (Department of Health 2012). Department of Health (2007) asserted that significant benefits to individuals and

healthcare systems could be obtained by supporting patients to achieve effective self-management. However, Armer, Brooks, and Stewart (2011) asserted that PLWL perceived their self-management support to be mostly limited to information delivery, which does not ensure understanding or action, and discussed the need for more comprehensive support.

The way information is presented, support services are offered and products are designed could significantly impact how PLWL manage their condition. This paper reports on the development and application of user-centred design tools based on an understanding of behaviour change theories. These were used to uncover the needs of PLWL in order to define a support system that is useful and desirable to them.

User-centred design in Healthcare and Exploration of Patient Needs

User-centred design is an iterative process in which potential users are central to the development of solutions. The front-end of user-centred design includes decisions about what will be designed (whether it is a product, service or system), what it will do (function) and why this is needed (aim). These front-end decisions are critical for maximising the value for users and opportunities for innovation (Koen et al. 2002). In healthcare, user feedback is commonly sought for the evaluation of systems. However, McNichol (2012) asserted that research agendas or system functions are usually defined without patient input. Such late involvement of patients restricts their contribution to the design, since changing directions at later stages is not usually possible (McNichol 2012). The identification of unmet patient needs in healthcare has often been carried out using questionnaires targeted at patients, carers and experts (Moody 2015). However, not all needs can be explicitly articulated following such methods. Sanders and Stappers (2012) suggested deeper engagement with expected users to explore their latent and tacit needs. 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.

Behaviour Change for Lymphoedema Self-Management

Support approaches traditionally used in acute care, such as information provision alone, have been found to be ineffective in chronic conditions (de Silva 2011). As a result, de Silva (2011) asserted that it is necessary to shift towards behaviour-focused proactive support and co-creation of solutions with patients. Still, previous research has shown that most healthcare technologies are developed without explicitly mentioning any behaviour theory (Nunes et al. 2015; Sawesi et al. 2016).

A framework previously developed by Kopanoglu, Eggbeer, and Walters (2018) that presents a multidimensional behaviour change towards self-management of lymphoedema was used in the thematic analysis of this study. The framework was developed by analysing the literature about the experience of lymphoedema self-management and correlating behaviour change theories (Kopanoglu, Eggbeer, and Walters 2018). It draws heavily on the Stages of Change model of Prochaska and DiClemente (1983) and Self-Determination theory of Ryan and Deci (2000).

Self-management is a transition where individuals' behaviour and needs change. Previous research has proposed supporting patients by using strategies that match their motivational readiness for change (DiClemente & Prochaska, 1983) and their activation for self-management (Hibbard and Tusler 2007). However, the specific support needs of PLWL, and how these change during the process of becoming experts of their condition, has not been addressed.

Methods

A summary of the study methods, objectives and results is shown in Table 1.

Table 1. Overview of the study: methods, objectives and results

Methods	Objectives	Results
Literature Review: Systematic selection of the literature describing the experience of PLWL. Thematic synthesis of the 31 selected articles.	<ul style="list-style-type: none">- Identify what is known about living with lymphoedema.- Develop ways of engaging with PLWL to understand how their self-management might be supported via products and systems	<ul style="list-style-type: none">- Barriers to and facilitators of self-management in the lymphoedema journey- Scenario-based probes to envision alternative futures for self-management support during the interviews
Interviews: Interviews using scenario-based probes with 9 PLWL. Thematic analysis.	<ul style="list-style-type: none">- Explore PLWL's real experience to better understand their needs.	<ul style="list-style-type: none">- Changing needs of PLWL in their transition towards becoming experts of their condition

Literature Review of the Experience of PLWL

Articles were screened and selected systematically following PRISMA protocol (Liberati et al. 2009). The literature search reviewed articles from across seven databases (Pubmed, PubMed Central, Cochrane Library, CINAHL the Cumulative Index to Nursing and Allied Health Literature, Embase and MEDLINE) published between January 2007 and November 2017. Thirty-one articles were included in the qualitative analysis (Figure 1).

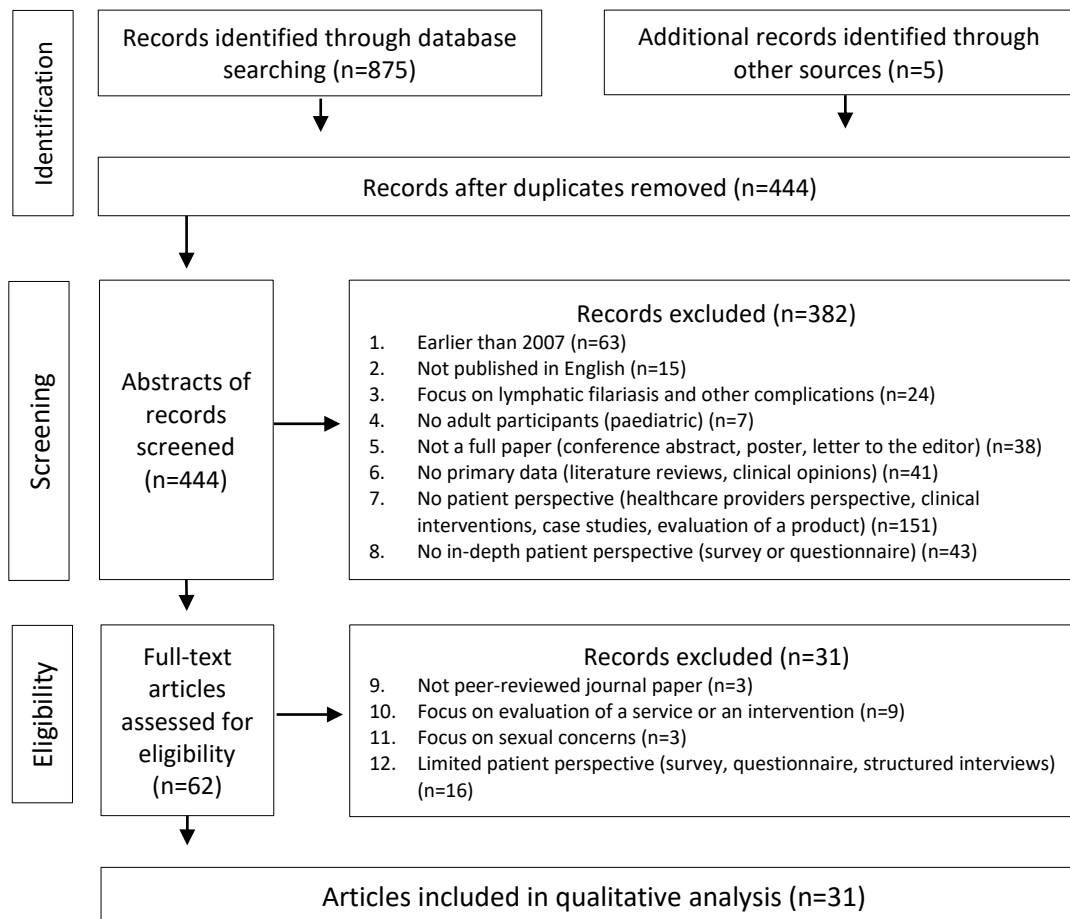


Figure 1. Systematic Screening Process of the Literature: Experience of PLWL

Publications were coded following a three step thematic synthesis as described by Thomas and Harden (2008). Articles were reviewed to identify thematic clusters which were then organised to create descriptive themes. The themes were categorized into corresponding behavioural processes and stages. Following this, themes were analysed to identify facilitators of and barriers to lymphoedema self-management.

Interviews via Scenario-Based Probes

A semi-structured interview script was developed and tested in a pilot interview conducted with a member of a lymphoedema support group. The interview protocol was refined and used in individual face-to-face interviews via scenario-based probes.

Scenarios in this study intended to facilitate the communication of envisioned futures with end-users, as suggested by Carroll (2000). Scenario-based probes were used to elicit meaningful discussion about how lymphoedema self-management might be supported. The probes included a persona, scenario sheets and cards describing each component in the scenario. The persona described someone recently diagnosed with lymphoedema, and was included to sensitise participants and facilitate conversations about their needs at the time of diagnosis in comparison to the time of the interview. Further, the combination of persona and scenario was intended to better equip participants to envision alternative futures outside of their own experience. The cards encouraged the participants to discuss their perceptions of the separate support features in the scenario and to compare them with each other.

The interviews started with open questions about how participants managed their lymphoedema: how they felt about lymphoedema; learned self-management; communicated their condition with others; and expectations from better self-management support. The persona was introduced, and participants were asked for suggestions to support her based on their experience. Following this, the scenario – a day in the life of the persona - was introduced. Participants were encouraged to add ideas and suggestions to the scenario, and compare their own experience with that of the persona.

Participants were selected through convenience sampling. Nine interviews were conducted between April and August 2018, each lasting from 40 to 100 minutes. Seven interviews were carried out with participants from a local support group in the United Kingdom, with a further two at the patient day of the International Lymphoedema

Framework Conference (Netherlands, 2018).¹ Participant characteristics are shown in Table 2. A photographic record was created following each interview to document how participants sorted the cards. The rankings of the cards were analysed in relation to participant comments while sorting the cards. Interviews were audio recorded, transcribed and iteratively coded. Data collection and analysis were undertaken concurrently.

Table 2. Interview participants²

Pseudonyms	Age (years)	Affected Limb	Lymphoedema Type	Years Since Diagnosis	History of Cellulitis
Sarah (pilot)	70-80	Leg	Primary	>40	No
Elizabeth	60-70	Leg	Primary	>15	No
Laura	30-40	Leg	Primary	>5	Yes
Helen	40-50	Leg	Primary	>20	Yes
Lesley	70-80	Leg	Primary	>10	Yes
Jennifer	60-70	Leg	Secondary	>30	Yes
Mary	60-70	Leg	Secondary	>5	Yes
Carol	60-70	Leg	Secondary	>10	No
Margaret	70-80	Arm	Secondary	<5	No

Results

Literature Review Results

The list of the 31 articles included, their participant distribution, geographic origin,

1 Ethical approval was given for the study following Cardiff Metropolitan University's procedures. All participants provided informed written consent prior to interview participation.

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

aims, inclusion criteria and data collection methods are provided in the supplemental material.

Barriers to and Facilitators of Lymphoedema Self-Management

Barriers to and facilitators of self-management were identified through the five main categories of change in lymphoedema self-management: competence; autonomy; habit; psychological; and social. These were provided in relation to the synthesised article in supplemental material.

The competence is the development of self-management skills, and the extent of feeling physically and intellectually capable of managing. Lack of clear diagnosis and inconsistent information were fundamental barriers. Further, even after information was provided to the individuals, this was frequently not perceived adequate for learning self-management.

Autonomy describes the extent of feeling responsible, motivated and in-control of managing one's own condition. Autonomy barriers arose from difficulties in prioritising self-management among other duties and not having clear expectations. The ineffectiveness of self-management or not being able to see its benefits was a critical barrier.

Habit is the actual performed self-management and the extent of this becoming a habitual action. Reasons for not having a self-management routine included: not having enough energy, time, discipline, or knowledge on how to build such habits. A frequently mentioned strategy to maintain a routine was to adapt and make self-management feasible for individuals' lifestyle

The psychological state of the individuals in relation to their chronic condition is another component. PLWL described their perception of being criticised about their limb appearance, which led them to hide their condition and, for some, led to isolation.

Their diagnosis journey and the causes of lymphoedema was highly influential in their psychological state.

The social component is related to individuals' adaptation to changes in their identities after the diagnosis of their chronic condition and their support network. Lymphoedema treatment was not available for many, and those who received it had to fight for access. Healthcare professionals were perceived to have limited knowledge about the condition and to underestimate its burden. Another barrier arose when individuals perceived self-management as conflicting with their identities in family, social life, or work.

Development of the Scenario-Based Probes for the Interviews

The persona was developed as the actor of the scenario, via the voices of PLWL from the literature review. Each described attribute in the persona aimed to invite participants to discuss specific themes founded in the literature review (Figure 2).



Figure 2. Foundation document for the persona (left) in reference to the literature review and persona with annotated numbers to the foundation document (right)

The first author of the paper, who is a product designer, generated alternative concepts for supporting lymphoedema self-management. In this concept generation, the

author/designer intended to address the barriers identified through the literature review and to find ways to support the self-management of the persona. A list of the concepts in relation to the five main categories of change and the distinguished barriers were provided in the supplemental material. Each interviewee was invited to suggest additional concepts, which were added to the probes prior to the next interview. After the fourth interview, no additional concepts emerged.

These features were incorporated into an everyday scenario lived by the persona (Figure 3). The features and technologies involved in the scenario were intentionally left undefined so that participants would feel able to interpret the scenarios based on their own understanding. Individual self-management support features in the scenario were introduced in a card format (16 cards in total). Participants were asked to sort the cards into three categories: not so important, moderate and most important.

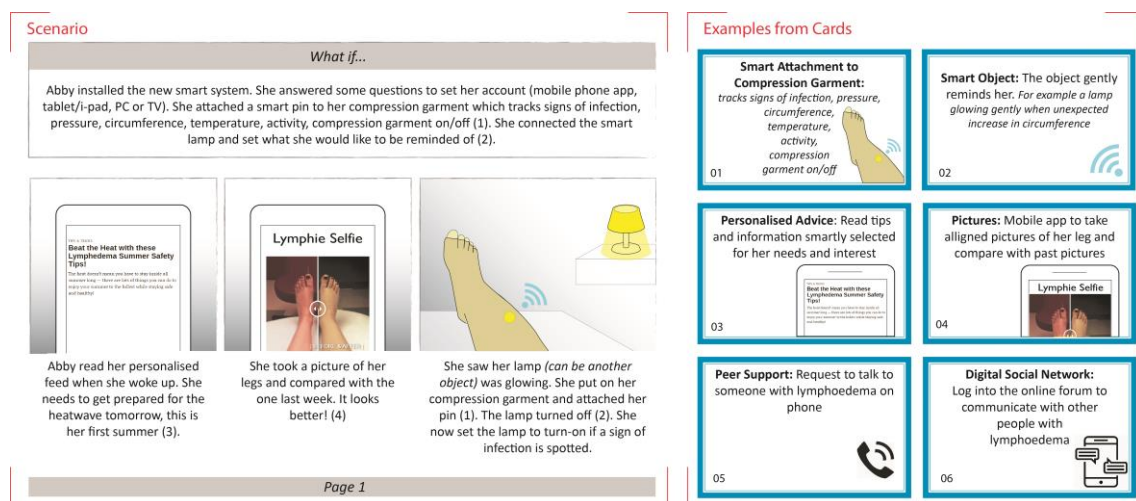


Figure 3. First page of the scenario and a selection of cards used in sorting activity

Interview Results: Self-Management Needs of PLWL

The needs of the participants were found to change during their transition towards self-management. Three stages were identified to present these changing needs (Figure 4).

The Novice stage represents individuals just after lymphoedema diagnosis, until they

start managing at home. The Experimental phase is when they expand their understanding and strategies via trials. At the Expert stage, individuals are able to distinguish onsets and adapt their management accordingly. Self-monitoring appeared as an additional theme in relation to the five main categories that were identified from our synthesis of the literature.

	Novice Stage	Experimental Stage	Expert Stage
SELF-MONITORING 	Learning to listen to the needs of their lymphoedema	Objective or subjective monitoring to explore the influence of alternative strategies and possible triggers	Ongoing monitoring: Familiarity can make it difficult to recognize when strategies are ineffective
COMPETENCE 	Hands-on demonstrations of fundamental management strategies for developing skills	Testing, observing and reflecting to learn alternative strategies and possible triggers	Refreshing and expanding management strategies
AUTONOMY 	Setting viable expectations from self-management	Goal setting	
	Exhibiting how management strategies work		
	Showing the benefits of self-management strategies		
HABIT 	Prioritizing fundamental self-management strategies	Adaptation of management strategies to balance with other life priorities	
	Integration of management strategies to everyday life		
PSYCHOLOGICAL 	Adjusting to new limitations and changing roles		
	Experience of other PLWL to normalise the condition		
	Support when swelling increases or management is ineffective		
SOCIAL 	Access to lymphoedema therapist	Follow-up appointments with lymphoedema therapists	
	Public awareness about lymphoedema		
	Meeting other PLWL for inspiration and advice		

Figure 4. The Changing Needs of PLWL towards Self-Management

Self-Monitoring

Participants' self-monitoring primarily relied on subjective measures including checking appearance, size, and visual clues in comparison to memory and sensations:

'You can feel it. It's like when you're feeling unwell, it's like an instinct' (Mary). Three of the participants described how they measured their limbs:

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)

Helen mentioned the extra work required for taking measurements: '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"'. Subjective and objective self-monitoring measures described by PLWL are listed in Table 3.

Table 3: Subjective and Objective Ways of Self-monitoring in Lymphoedema

Subjective	Local Sensations (pain, heaviness), Overall Body Sensations & Energy Level (feeling unwell), Size & Appearance (naked eye, pictures, fit of clothes & shoes, gauge with hand, compared to visual cues) Texture (feeling while creaming & massaging), Mobility & Flexibility
Objective	Circumference tape measurements, Copies of the clinical measurements, Weight, Temperature during cellulitis, Marking the borders of the area during cellulitis

Mary mentioned that her perception of the changes in swelling did not always match the measurements taken by lymphoedema therapists: '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 how they learned to monitor early sensations and tried to avoid worsening of their swelling via various strategies. Self-monitoring was employed to analyse the reasons of fluctuations in their swelling. Participants also explained how their preference in self-monitoring changed along their journey: initially objectively for exploring triggers and understand physical sensations associated with a change in condition, followed by subjective measures when they became competent in distinguishing onsets. Sarah emphasised that even after individuals became experts in their own conditions, there remained an ongoing need for monitoring in the long-term: ‘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’.

When the scenario was presented, participants described how they perceived the possible benefits and drawbacks of the smart self-monitoring concepts.

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, concerns about being obsessed with measurements and obsolescence of such tracking devices were also highlighted:

I wonder if that would become obsessive... 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. (CAROL)

The possible emotional drawback of seeing the increased measurements was another concern and a reason for preferring subjective measures instead of a smart self-

monitoring concept.

Competence

Even though participants thought that they learned specific skills during their consultations, they reported that they found some of these difficult to implement later at home: 'No one showed me... you got no idea how it would feel... If it can be demonstrated as well as explaining, then it won't be open to misinterpretation' (Elizabeth).

After gaining the fundamental skills for lymphoedema self-management, learning self-management was an active experimental process of 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.

While talking about the scenario, online information sources were perceived as being beneficial once the expert stage was reached, but as potentially inappropriate for a novice: 'I think this [online peer support concept] is dangerous at times because there is awful a lot of information that's wrong' (Jennifer).

In response to the concept of tracking signs of cellulitis 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 experienced common symptoms such as redness, pain and temperature. They eventually learned to distinguish the signs specific to their body. However, healthcare professionals did not always recognise such 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 signs: ‘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”’.

Autonomy

Participants frequently mentioned the importance of seeing the benefits of self-management for motivation. ‘For me, it's to see your leg is responding... you know that motivates you to continue’ (Helen). Understanding the physiology of how management strategies work was critical to sustain behaviour in the long-term:

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. (Carol)

Mary described how she was seeking alternative strategies, despite not seeing the desired benefits from self-management: ‘If you are swooning 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’ Laura emphasised the importance of setting viable expectations from self-management:

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 task and to remind you that this is going to take time. (Laura)

As a response to the goal-setting concept introduced in the scenario, participants explained how they perceived its benefits: ‘It 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’ (Lesley).

Habit

Participants described how they started by wearing compression garments, and then added various strategies to their self-management gradually: ‘you set up 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 adaptation, the balance between self-management and life priorities was identified as critical. Awareness of behaviours that worsened their lymphoedema gave participants power in decision-making about self-management. In some cases, participants would practice avoidance based on the chances of worsening their condition. However, they did not always choose to avoid them; some explained that they would undertake activities, and compensate for the effects within their everyday routines: ‘I know, I'm going to do a lot today and will be in pain, but I don't mind’ (Lesley).

Two main approaches to self-management influenced by participants’ personality traits were distinguished at the Novice stage. Some participants started by diligently doing everything that they were advised to do. Others tried out some of the

strategies to find the minimum required self-management that would allow them to sustain their desired quality of life:

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 `ohh can do it without it for a day or so. (Jennifer)

Ultimately, participants with both approaches adapted their self-management in order to integrate it into their life in a balanced, effective and feasible way. 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 were not keen about the reminder concept included in the scenario. Laura explained 'Personally I think that would annoy me. It's about maybe in the beginning... you don't need at the later stages'.

Psychological

Participants who acquired lymphoedema after cancer treatment expressed negative emotions caused by insufficient communication of the risks of lymphoedema prior to their 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). They mentioned peer support as helpful in overcoming such psychological barriers: 'Listening to those people [support group] was therapeutic for me to sort my own problems' (Margaret). The permanence of the condition was influential in their perception of self-management: 'Still, it [self-management] is not a cure. It's up to us to come to terms with it, deal with it' (Elizabeth).

Inability to understand and control swelling 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 look after them and that's when I got miserable' (Carol). Mary described how understanding the triggers helped her to accept such 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'.

Social

Participants felt that lymphoedema 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'. They described their choice of clothes to hide their swelling from others: 'I hide my legs because people stare, and that's horrible' (Lesley). Mary expressed how her need to conceal her condition had changed gradually: 'Today I wear sandals. This is the first year I wear sandals and show my stocking. Because I was so conscious of it'.

All participants explained the benefits of meeting other PLWL: 'That's how you learn tips and tricks. See that you're not alone' (Carol). Success stories of other PLWL were seen as helpful in increasing participants' motivation: 'You meet some people that inspire you. Sometimes it is like you see someone and you think I can do that' (Helen).

While talking about the scenario, participants expressed their preferences about the medium of such 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 professionals could be risky and should be avoided, especially by novices:

‘If you're first diagnosed, the information should be coming from clinic... because there is so much misinformation out there’ (Carol).

The support of their lymphoedema therapist was fundamental to the participants. Still, most of the participants perceived their appointments as a measuring service instead of the treatment they desired: ‘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’ (Mary). Carol emphasised the time constraints limiting the provided support in lymphoedema clinics: ‘I've always think that the measuring system in clinic is so ad-hoc... They are very quick but they are later putting those numbers to the computer and that takes longer.’ Participants perceived that the 3D scanning concept could shorten the time needed for taking measurements in clinics, and Helen added that could ‘reduce the risk of having to redo your compression garments’. Lesley described her ideal lymphoedema consultation in a way that would complement her experimental learning:

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)

Some participants found the concept of sharing the self-monitored data with healthcare professionals beneficial: ‘It helps make you more active in your healthcare; you can have better dialogue with your healthcare’ (Laura). 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 raised concerns about

reliability of such technologies and how her lymphoedema therapist might perceive those: 'First of all, my clinician would not be happy about that'.

Discussion

Interviews were conducted with participants living in the United Kingdom (n: 7) receiving care in the National Health Service (NHS) and in the EU (n: 2). All participants were women. These may limit relevance to other countries with different health care systems and people of other cultures or language groups. Yet, our literature review included publications from around the world (see supplemental material) and represented wider demographics. The scenarios were intentionally not developed design solutions and only the perceived usefulness of these features were investigated. Despite these limitations, our interviews via scenario-based probes provided rich insights about participants' experience and their changing self-management needs.

Scenario-Based Design Probes in Exploring Needs of PLWL

Scenario-based design probes enabled the exploration of not only how self-management has been for our participants, but also how it might be supported by future products and systems. Before the introduction of the probes, participants' suggestions were limited to what they had previously used; the probes were seen to support participants to conceive and discuss an alternative future.

The scenarios were not constrained to known technologies, but included currently available components such as peer support groups alongside smart systems that participants had not thought of before, or believed that would not be possible. Hence, these scenarios helped to communicate future use-cases with participants, even before the development of prototypes. Therefore, insights were gained beyond participants' previous experiences to guide early design decisions for support systems.

The scenario-based probes were specific but flexible as suggested by Carroll (2000). That flexibility facilitated participants' manipulation of the presented features, which provided insights about their underlying goals and needs. As described by Cooper (2004) 'tasks change as technology change, but goals have the pleasant property of remaining very stable' (p.150). Hence, scenarios allowed focus to be placed on the intended future user experience, instead of specific design decisions and technologies.

Participants' interest in or adoption of technologies was not a recruitment criteria and the interviews revealed a wide variation in the propensity for technology adoption amongst participants. However, the scenario-based probes facilitated all the participants in discussing their goals associated with the scenario, detached from their interest or experience with technology.

Groeneveld et al. (2019) highlighted the challenges in involving patients in design for healthcare studies, given that most are not used to engaging in design activities for creating solutions. As discussed by Pascale, Sternin, and Sternin (2010) people who 'succeed against all odds' have been found most effective in co-creation. Hence, during the recruitment phase of this study, people who were proactively seeking solutions for their self-management by attending conferences and support groups were targeted.

The presented persona (someone at novice stage in self-management) further elaborated the conversations about participants' changing needs along their journey. Personas are commonly used within product development teams to empathise with the users, communicate user research and discuss design decisions. In this study, a persona was presented to the intended users themselves, PLWL, as someone recently diagnosed with lymphoedema. The persona in this study aided in sensitising participants to consider when they were first diagnosed, and engaging them in the scenario as co-

designers by having a segregated actor. Our behavioural approach in the development of the scenario-based probes allowed the exploration of the phenomena as a multidimensional transition with changing needs.

The Changing Self-Management Needs of PLWL:

Support that did not match individuals' stage-specific needs was not effective and could cause frustration. Self-managing lymphoedema required learning new skills and information about numerous everyday influential factors. Provision of comprehensive information about lymphoedema close to diagnosis could be overwhelming. At the Novice stage, fundamental strategies should be prioritised, while explaining viable expectations from these and how they work in relation to human physiology. Fu et al. (2016) explored the better delivery of knowledge to PLWL via videos, addressing the competence needs of novices. After the development of fundamental skills, participants increased their repertoire gradually by exploring alternative strategies and possible triggers. The participants of this study did not perceive self-management as something to adhere to; instead, they proactively explored strategies, and adapted and integrated these to their life. However, these experimental needs of PLWL in observing, reflecting, testing, and adapting management strategies in relation to self-monitoring have not been addressed before in the literature.

Most previous research in self-monitoring has addressed chronic conditions such as hypertension and diabetes in which monitoring by patients was recommended by healthcare professionals (McBain, Shipley, and Newman 2015). However, there were no guidelines or available products/systems to assist self-monitoring for our participants with lymphoedema. Monitored symptoms in lymphoedema could not always be associated to known factors, since the effects were not immediately recognisable or there were too many influential variables to consider. Moreover, Lette, Lette, and Fraser

(2007) argued that healthcare professionals were reluctant in recommending PLWL to take measurements at home. Our literature review identified only one article (among the systematically selected 31) that mentioned participants measuring limb circumference (Bogan, Powell, and Dudgeon 2007). Yet, three out of the nine participants of this study had been taking measurements for long periods. Self-monitoring experience of PLWL and the meaning of symptom tracking is presented in this paper, for the first time.

The participants of this study self-monitored to make sense of the fluctuations of their swelling, and to find alternative management strategies that were effective and feasible for them. Participants emphasised the psychological drawbacks when the results of self-monitoring did not match their expectations. Knowing the time required for getting a response from their lymphoedema and setting meaningful goals were highlighted as critical. They mentioned how the measurements could sometimes be different from how they perceived their swelling, underlining the importance of combining objective measures with subjective ones. Participants highlighted their ongoing monitoring needs, because when self-management became an everyday habit, they become less aware when strategies were ineffective.

Various self-monitoring systems in lymphoedema were suggested previously in the literature, including tape measurements of the circumference (Galiano-Castillo et al. 2016), water displacement for volumetric change (Lette, Lette, and Fraser 2007), bioimpedence for percentage of fluid accumulation (Ridner et al. 2014), and subjective symptom assessment (Fu et al. 2016). Each of 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.

Conclusion

This research has identified the needs to be addressed in the development of a self-management support system that is useful and desirable for PLWL. The meaning and experience of symptom tracking in lymphoedema, PLWL's transition towards self-management and their specific needs at different stages of this journey were presented in this paper. Support systems and products can only be useful and desirable for PLWL if they match their stage-specific needs and address all the presented six processes of change in self-management.

Scenario-based design probes have been illustrated as an appropriate way to uncover these needs of PLWL. The introduced design-probes allowed to explore the perceptions of PLWL about alternative self-management support and provided rich insights about their self-management experience. This research builds upon increasing rhetoric within healthcare for the provision of patient-centred solutions. However, despite this rhetoric, there are few examples of effective engagement with patients for the design and development of better support around chronic conditions, and none were found in relation to lymphoedema.

The approach to exploring needs via design-based probes presented in this paper could be applied across a wide spectrum of chronic health conditions. In the development of self-management support, individuals with chronic conditions should not be considered as passive receivers of information who are assigned to comply with a prescribed routine. Instead, they should be supported for being proactive problem solvers; who observe, reflect and adapt their management every day to integrate it into

their life. This change in understanding is critical to meet the real needs of people with chronic conditions in the design of self-management support systems.

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