

The meaning of success in lymphoedema management

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Key words

Intensive phase, lymphoedema management, maintenance phase, self-management, success

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Abstract

Background: Lymphoedema is a chronic disease that requires a lifelong management. Complex decongestive therapy is the recommended treatment, which consists of intensive and of long-term management phases. The goals of treatment can be different for the therapist or for the person who lives with lymphoedema. No study has examined the perception of treatment success of those who experience lymphoedema. Therefore, the aims of the study were to understand what people with lymphoedema consider to be the meaning of success in the intensive phase and in the long-term phase of lymphoedema management. **Method:** The biopsychosocial model for lymphoedema was used as a conceptual framework for this study. A phenomenological method, with semi-structured interviews and open-ended questions, was applied. Purposeful sampling was used to recruit people who live with lymphoedema of different aetiologies, stages and severities. The interviews were conducted in the long-term management phase for each participant. Content analysis was conducted using value and affective methods for the first cycle coding and axial coding for the second cycle. The most common themes that emerged from the data were hope; lack-of-clarity as to moving to the long-term phase of treatment; and empowerment and maintenance versus back to normal (acceptance versus hope). **Conclusion:** In the intensive phase of treatment, success means disappearance or improvement of the swelling and pain, and better function. In the maintenance phase, success was deemed as stability and not getting worse, but also, for some participants, disappearance of the swelling.

Lymphoedema affects more than 120 million people worldwide (International Lymphedema Framework [ILF], 2012). Lymphoedema is defined as an accumulation of protein-rich fluid in the interstitial tissue spaces. This causes oedema of a body part, which can lead to reduced movements and symptoms such as pain, numbness, heaviness, impaired function, psychological deficits and more (ILF, 2012). Lymphoedema may be life-threatening when an infection develops and, therefore, needs to be addressed as soon as diagnosed, in order to reduce the risk. It often develops into a chronic condition, which will require lifelong management (International Society of Lymphology [ISL], 2013).

Lymphoedema is defined as primary when the cause of oedema is intrinsic, within the lymphatic system. When the swelling appears from birth until two years of age, congenital lymphoedema will be

identified. When swelling develops from two to 35 years of age, the definition will be of praecox lymphoedema. Lymphoedema tarda is defined when it manifests after the age of 35 (Murdaca et al, 2012). Lymphoedema is defined as secondary when there is an external cause of dysfunction of the lymphatic system, such as surgery, trauma, infection and radiation therapy. The incidence of cancer-related lymphoedema is reported to be an average of 15.5%, where the incidence ranges from 4% after head and/or neck cancers and up to 30% after sarcoma (Cormier et al, 2010). Breast-cancer-related lymphoedema (BCRL) is one of the most studied aetiologies in lymphoedema literature and is reported to have an incidence of 20% (Hayes et al, 2010) when followed up until 18 months, but between 41% to 91% when followed up to 30 months (Armer et al, 2009). The difference between reports is due to different

definitions of lymphoedema and different follow-up periods (Armer et al, 2009).

The most common treatment for lymphoedema is complex decongestive therapy (CDT), which is performed in two phases. An intensive phase that aims to reduce the swelling and normalise the tissue pressure usually consists of skin care, daily bandaging, exercises and light massage, if needed. After the limb has stabilised, the person with lymphoedema enters the long-term phase in which he/she uses the tools they have learned, in order to maintain the results of the treatment (Lasinski et al, 2012). Other therapy options have been studied and include lymph pumps (Lasinski et al, 2012), laser therapy (Ridner et al, 2013), aquatic therapy (Tidhar and Katz-Leurer, 2010), acupuncture (De Valois et al, 2012) and others (Rodrick et al, 2013).

The patient definition of success of treatment, either in the intensive phase or in the maintenance phase, has not yet

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been reported. Minimal clinical important difference (MCID) is a term that had been used in several quantitative studies that examined outcomes of lymphoedema treatment. Standard error of measurements, small real difference and minimal detectable change are terms that are applied to the capture of a true difference that was beyond the error of measurement (Taylor et al, 2006, Devoogdt et al, 2010, Katz-Leurer and Bracha, 2012). However, no study has yet reported on what patients consider to be a successful treatment and what they consider meaningful.

Few qualitative studies have examined the experiences people diagnosed with lymphoedema go through when dealing with the consequences (e.g., symptoms) and the management of lymphoedema. Themes that emerged from a study on women who had BCRL included: living with perpetual discomfort, confronting the unexpected, losing pre-lymphoedema being and feeling handicapped (Fu and Rosedale, 2009). Another study found that physical limitations were most common in the reports of women, with two subthemes of: 1) being cautious and aware; and 2) feeling frustrated with physical dependency (Radina, 2009). Another concern that was found by Ridner et al (2012) was that lack of support from healthcare providers and lack of knowledge cause them to minimise the impact of lymphoedema. Financial issues such as high cost of treatment (Person et al, 2006), and loss of work (Bogan et al, 2007; Perera et al, 2007) were other dimensions that were stated. Emotional responses that were reported by Person et al (2006) included themes of shock, fear that the cancer had returned or that something was terribly wrong, as well as abandonment and despair (Person et al, 2006). Regarding the perception of management of lymphoedema, researchers found themes such as seeking effective treatment (Carter, 1997), having nowhere to turn, searching for answers (Bogan et al, 2007), and failing to adequately treat (Person et al, 2006). Specifically, sleeves were experienced as inefficient and not worth continuing wearing (Wanchai et al, 2012) and bandaging was found to be constraining, tiring, time-consuming, heavy, bulky and leading to feelings of clumsiness and a restricted life (Morgan et al, 2011). Self-management was perceived as challenging (Bogan et al, 2007) and excessively time-demanding (Heppner et al, 2009). Individuals expressed concerns with making daily care feasible, incorporating lymphoedema care

into a daily routine (Fu, 2010), prioritising self-care over care of others, as well as making a commitment to self care (Radina et al, 2014), and making modifications in participation in order to continue their leisure time with their families (Radina, 2009).

The fact that women reported their challenging experience of lymphoedema does not in any way mean that their perception of successful outcome will address those issues. A woman can experience fear and loss of self; however, she might feel that success is being able to hold her grandchild or reduce pain. Even if we, as clinicians and healthcare systems, think we understand what people with lymphoedema experience, it does not mean that their definition of success is obvious. The only way to explore what a person with lymphoedema feels and values as a success is to ask him/her to tell us. Therefore, new research is needed to address this issue in depth. This review helped the authors to focus interviews on issues that concern individuals living with lymphoedema, and hopefully, with this knowledge, clinicians can grasp this unknown perception.

The biopsychosocial model for lymphoedema (*Figure 1*) is a theoretical framework, which looks at all aspects of the management of lymphoedema. The concepts of social support and problem-solving are protective mechanisms that relate directly to the outcomes of lymphoedema management and influence the concept of coping effectiveness and symptom management as well. The objective (limb volume change) and subjective (symptoms) concept and the coping effectiveness and symptom management concept influence each other and directly the outcomes of lymphoedema. At the top of *Figure 1* are the predisposing factors that can influence each of the concepts (Armer et al, 2003; Armer, 2010). This model helps clinicians to understand what concepts come into play when treating a person with lymphoedema, which can help guide the development of the interview in a way that will encompass all these issues. Nevertheless, an open mind should be kept, as the person who has lymphoedema may consider different outcomes as his/her goals or define success differently than what the therapists or the healthcare system would.

Therefore, the purposes of this study were to understand:

- What do people with lymphoedema consider to be the meaning of success in the intensive phase of lymphoedema management?

- What do people with lymphoedema consider to be the meaning of success in the long-term phase of lymphoedema management?

Method

Study design

To understand what people with lymphoedema consider as the meaning of a successful treatment, a qualitative study design was used. Researchers who study lymphoedema have used different methods to approach the subject (Dine et al, 2011, Wanchai et al, 2012, Meiklejohn et al, 2013); however, a phenomenological method is the most frequent method used to examine experiences of people with lymphoedema (Person et al, 2008; Heppner et al, 2009; Fu, 2010). As this study was aiming to explore what people feel, think and value as a successful treatment, this method seemed to be the most suitable for use in this study. Phenomenology as described by Richards et al (2012) is a method that explores individuals' experiences. The perception is that of the person who is going through the lived experience; it does not deal with events or facts, but rather the meaning perceived by the individual (Crabtree, 1999).

Lack of ability to generalise the conclusions of the study is a weakness of this method. Overstating of the conclusions needs to be avoided, as this method is very focused on the individual experience. Different factors come into play, which will need further investigation with a different research design to enable generalisation of the findings (Grossoehme, 2014).

Subjects

People with lymphoedema were recruited to the study until data saturation was obtained. A purposeful sampling was used in order to capture different aetiologies, areas of swelling and gender that can manifest differently and, therefore, would hopefully encompass variation in experiences, aspirations and expectations of people living with lymphoedema. People were included if they spoke Hebrew, had gone through intensive lymphoedema treatment, and were in the long-term management phase.

Data collection and data analysis

In order to capture a variety of people with lymphoedema who represent different groups, emails were sent to physiotherapists who specialise in lymphoedema management throughout Maccabi Healthcare System in the South district of Israel. The physiotherapists

were asked to look for people with lymphoedema who could participate in the study according to the inclusion criteria and a discussion was conducted regarding the suitability of the participants. Once decided, the primary investigator asked permission from the clinic managers to use their clinic for the interviews, and the physiotherapists asked the participants if they were willing to be interviewed; if they agreed, they were asked for permission to give the primary investigator their contact information for scheduling the interview.

All of the interviews were conducted by the primary investigator. Most of the interviews were performed in the participants' homes; one asked to meet in the clinic, and one at a coffee shop. Each interview took 45–90 minutes. Before the interview, all participants signed an informed consent and were informed about the study procedure (elaborated in *Table 1*), anonymity and confidentiality.

Semi-structured interviews with open-ended questions were used in the interview which followed the interview guide presented in *Table 2*. This guide was based on Leventhal's Self-Regulation model (Cameron and Leventhal, 2003) from understanding the cause of an illness through placing goals and coping. The guide was based on primary researcher's personal experience in treating people with lymphoedema, and the conclusions of qualitative studies about the experience of people with lymphoedema. After conducting a pilot interview with the guide, some questions were refined and some probes were added. An audio-recording was used after the participant's consent was received using two instruments to be sure that all data were captured.

Analysis

The content analysis approach was used once all verbatim transcription was completed. After reading thoroughly with an open mind, holistic codes were given, to grasp basic themes without yet analysing the data line by line. It gave a sense of what was going on before diving into the text (Saldana, 2012). Thereafter, the transcripts were read, word-by-word, with the holistic codes in mind and analysis began with first cycle codes. Attribute codes were used to identify the participants (e.g., severity and grade of lymphoedema, aetiology, time since diagnosis, phase of treatment, etc.). Two main first cycle codes were used: value coding, which represents values, beliefs and attitudes and helps to understand what

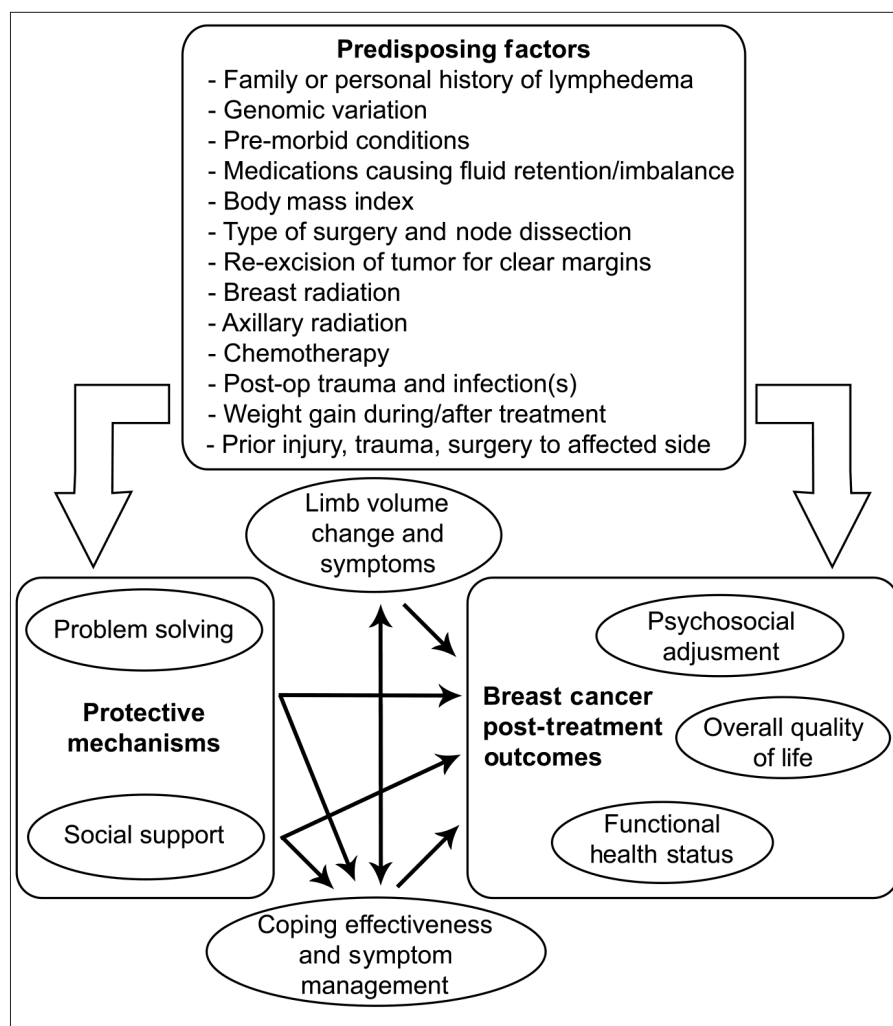


Figure 1. BioPsychoSocial model of secondary lymphoedema (Armer, 2010).

people considered important or meaningful. Attention was paid, while interviewing the participants, to the possibilities that the person reflected on what he was told and taught by his/her mentor or his/her therapist; therefore, probing was used in trying to differentiate between the therapists' values and those of the participants. Affective codes, and in particular emotion codes, were used; these are defined as expression of emotions that were presented by the participant or represented by the researcher (Saldana, 2012).

Reflexivity was used as the interviewer is a therapist and needed to be able to put aside his/her values and beliefs and let the participant share and feel comfortable and not be judged by his/her response. After the interview was over, an open discussion ensued and specific advice was given to the participant, as appropriate. This way, the interviewer could hold to his/her opinion, advice, and other questions or clarifications that she wanted to share, but that could have compromised the sincerity of the interview. This was a part of the

ethics committee request as to the fact that if the participant is bringing up dis-satisfaction from the healthcare services he/she should be given answers and may be referred back to therapy, if needed).

Once the first cycle coding was accomplished, a matrix of all questions on all participants was created and eclectic coding was used. This method is defined as a hybrid exploratory method (Saldana, 2012) and helped the transfer from the first cycle to the second cycle coding. This process used axial coding for the second cycle, with the purpose of finding the dominant themes that arise from the first and eclectic codes.

For validation, the primary investigator recruited and met with two content experts (lymphoedema therapists who had more than 15 years of clinical experience; one worked in Maccabi Healthcare Services and the other one worked in a hospital; and none of them treated any of the study participants). The first cycle codes, the second cycle codes and the themes were discussed thoroughly,

Table 1: Protection of human subjects.

The research proposal was submitted to the ethical board of Maccabi Healthcare Services and the IRB of Missouri University. Permission to interview patients in the clinics and their homes was obtained from all physiotherapists and managers who provided health care to the patients who were interviewed. Participants were asked to sign a consent form in which they were informed about the purposes of the study and the design, and the people who would be involved and exposed to the data. The participants were aware that they could refuse to answer questions and that they could ask any question before, during and after the interview. They knew that they can withdraw at any moment they choose. They were informed that their identifiers would be removed for publication, and all efforts would be conducted to assure anonymity and confidentiality.

Table 2: Interview guide (adapted from Leventhal’s Self-Regulation model; Cameron and Leventhal, 2003).

- Think back to when your arm started to swell. Please describe how you felt at that time.
- What were your concerns?
- Whom did you turn to? What was the treatment plan?
- What did you expect from your treatment? What would have satisfied you regarding outcomes?
- When were your goals met with the first intensive therapy?
- What did you expect from the maintenance phase? How did you think you would maintain the results of the intensive phase?
- What would you consider to be a good, meaningful outcome? A success?
- After all that you have been through, what would be a meaningful outcome for you?
- What do you think you can do in order to reach this goal?
- In an unlimited resources world - what do you think would have been the ideal program with the best results for you?
- How different are your goals from the goals of your therapists? After the intensive therapy? Now, in the long-term phase?
- How does your experience with lymphedema influence your definition of success?

trying to validate the conclusions of the investigator while going back and forth to the quotes of the participants’ views and experiences, and accordingly, changes were made with agreement. Furthermore, two of the participants were contacted again and were asked if the themes and conclusions represented their perspectives; these participants validated the themes and conclusions.

Results

Ten people (three men and seven women) diagnosed with lymphoedema were interviewed. Their lymphoedema was due to diabetes, breast cancer, skin infection; obesity, associated with lipoedema, or primary in origin. The time since lymphoedema diagnosis ranged from one to 35 years. All experienced at least one intensive therapy,

with most having more than one, with an averaged period of one month (ranges of visits from daily to twice a week, however, the bandages were on for 24 hours a day, every day during the intensive treatment period) and all were in their long-term phase of therapy.

The first aim of the study was to understand what people with lymphedema consider to be the meaning of success in the intensive phase. Two themes emerged from the data:

- Hope
- Lack of clarity as to moving to long-term phase of treatment.

When asking the participants about their response when they first saw the swelling, subcategories of detachment and bad feelings/experiences emerged.

A 54-year-old male shared his experience: “When my leg swelled up I wasn’t worried.

It was just the pain. The swelling caused pain and I couldn’t move and couldn’t work.”

Some of the participants had gone through a long and exhaustive journey to be diagnosed before being referred to treatment.

An 80-year-old retired school manager told us: “I was actually rolled from one physician to another. For years, I walked around with swollen and painful legs and actually started to feel that I had elephant’s legs — electric poles.” After these journeys and finally being referred to a treatment, hope can be expected to arise.

Hope

A 77-year-old retired woman who had breast cancer treatments 30 years earlier, but had lymphoedema only in the past 2 years, explained about her expectations from treatment: “I wanted for a miracle to happen and that the swelling will disappear.”

A 35-year-old woman who was a mother of two children, who was born with lymphoedema, told us that before she went into her first physiotherapist as an adult: “I wanted to preserve the situation or improve it. I expected her to explain to me. I expected to be better.”

All participants walked into the physiotherapy clinic with the expectation to get better.

Lack of clarity about moving to the long-term phase of treatment

When asking the participants about the goals of treatment, and whether their goals met the physiotherapist’s goals, all answered that the goals were the same. The plan of treatment was clear to most participants and included daily bandaging (by the therapist and by the patient or a caregiver and manual lymph drainage). One woman talked about a regular assessment and measurements.

Even though the plan of the intensive phase of the treatment was clear, the experience of moving into the long-term management left the participants with feelings of lack of clarity and abandonment. Only two participants felt that the decision of treatment cessation was a joint one (therapist’s and patient’s). The remaining participants felt that the cessation of intensive treatment was an administrative decision, the treatment quota was over, or that it was a professional decision by the physiotherapist. A 75-year-old woman shared: “The therapist said that the treatment was over after one month. I would have liked to continue more to feel that there is no need

for more. But they give only 10. They (the “system”) won’t give more than 10.”

The participants in this study were full of hope before they started the intensive therapy. They defined the meaning of success as an improvement, or disappearance of the swelling. However, there was lack of clarity as to the transition to the long-term management phase.

The second aim of the study was to understand what people with lymphoedema consider to be the meaning of success in the maintenance (long-term) phase. Two themes emerged from the data:

- Empowerment
- Maintenance vs back to normal (acceptance versus hope).

Empowerment

Undoubtedly, all participants managed their lymphoedema. It seemed as if they had incorporated the management into their life routine. All of them used compression (garments or bandages). One woman exercised on land, three in water, two performed self-massage and one used a compression pump.

When they talked about their self-treatment, they knew what they needed: what kind of garment; how many times to exercise; what makes them stable. Their definition of success for the long-term management was “not getting worse”, “stable”, “maintain”.

When an 80-year-old woman was asked how she achieves the goal of maintaining, she said: “First of all, walking in the water three times a week; receiving my rights: receiving treatments when I need and changing garments every six months.”

When she was asked what would she consider the perfect plan in a perfect world she said: “To receive a massage every week and even twice a week, compression bandages, and garments. If I will have that, I will be happy.”

In a perfect world with no limitations, subthemes that emerged were: cure, massage, compression garment and bandages that will fit perfectly and will not be cumbersome, regular checkups and a free membership to the pool.

All participants treated themselves. They did not let the swelling get out of control. Does that mean they accepted their lymphoedema as a chronic condition for life?

Maintenance vs back to normal (acceptance vs hope)

Moving into the long-term phase might have

been unclear for the participants; however, once they were in it, they seemed to know exactly where they were going and what they needed.

When they were asked about their expectations from the long-term phase, they talked about acceptance, about having no other choice, but dealing with their condition. One of the participants, a 64-year-old said: “I understand that the swelling will not disappear. I understand that I need to work my lymphoedema every day — this is my work (every morning self-massage and exercises, during the day I wear my compression garment, sometimes I bandage at night and exercise in the pool as well).”

For a 77-year-old woman, it was more than acceptance; one could understand that she was tired of hoping. She said: “Expectations faded away. I still had hope that the compression garment and the lymph pump will make the swelling go away. I had hope all the time. I kind of lied to myself over the years.”

The participants learned to accept their condition and got tools of how to treat their lymphoedema in their long-term management.

However, when we asked a 64-year-old woman about her definition of success, she answered that this was related to the swelling disappearing. She accepted that she needed to work hard, but not really that this chronic problem may not go away: “I don’t feel good. I want a massage every 2 weeks. I understand this is only for my morale but my therapist is a specialist and on my own it is not precisely as it is needed to be done.”

Discussion

While trying to analyse and integrate the data, a strong feeling of satisfaction arose, as all participants found some way of dealing with their chronic condition. However, one could not help feeling sad, specifically, due to the tiredness of these people who expected to get better, defined the meaning of success as disappearance of symptoms and getting their life back, and whose expectations faded away in time and over treatments. The enthusiasm that they had at the beginning when they had found someone who could help them, disappeared; but then, they realised over the years that lymphoedema can get worse, and that having it under control and not having exacerbation is a success. Although people do accept their lymphoedema, one could feel there is a disappointment component

in it. When trying to figure it out, it felt as if all the participants were not content with the transition management into the maintenance/long-term phase.

In an article by Bordin (1979), a working alliance was introduced, in which there was an alliance that developed between a psychologist and a patient which, if strong, was proven to be a major factor in changing behavior in psychotherapy. Bordin argued that this alliance can be generalised across therapy systems. Bordin suggested three components to a therapeutic alliance:

- The therapist-patient agreement on goals of treatment. All participants in our study stated that there was agreement on goals of treatment in the intensive and the long-term management
- The affective bond between patient and therapist. All the participants either stated that they were fond of their therapists or respected her decisions and that he/she was nice, or one could understand from the way they described the journey that they felt a bond with their therapist
- The therapist-patient agreement on interventions. This component was also reported in the interviews, and there was an agreement on ways of intervention in the intensive and in the maintenance phase. However, the transition into the maintenance phase seemed to be lacking agreement. One could feel the disappointment when the treatment ended, as if they were left alone to deal with their problem. The participants said that sessions were ended by the system, the therapists, but not in an agreement that it was time to end.

One therapist who validated the themes and the conclusions from the data felt angry that, although the participants seemed to know exactly what was good for them, and how to treat themselves, they felt unfulfilled with the “system”. She felt that there is a need to match expectations of the treatment process, as well as goals and over the period of sessions.

Bachelor and Salame (2000) argued that the therapeutic alliance is developing over the process of treatment. Therefore, it could be that checking expectations and explaining process of treatment should evolve as well. This can be done while assessing (measuring and checking symptoms) the patient during the treatment period and offering objective feedback (measurements of volume, wound healing status, function score, etc.), which

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relates to the goals of treatment, reassessing the programme with the patient, and trying to make decisions together.

The second therapist who validated the themes mentioned that it was wonderful to see the reported independence that emerged from the interviews. Overall, the researchers believe that most of the components of the therapeutic alliance existed throughout the treatment process for the participants in this study. However, the therapist-patient agreement component, specifically the transition from intensive to long-term management, was lacking clarity and generated negative feelings by the participants.

Conclusions

Only 10 participants were interviewed as part of this study; therefore, conclusions are difficult to generalise as participants were expressing their own experience and views.

In the intensive therapy phase people are hopeful and optimistic as to achieving good results (disappearance or improvement of their lymphoedema). Most of the participants experienced more than one intensive treatment period, but each time there is still hope for improvement. The meaning of success in the maintenance phase seemed to depend on whether there was a true acceptance of the chronic condition; in this case, success meant stability (not getting worse), while those who still had hope wished for things to go back to normal. Either way, empowerment was a strong theme: people knew how to treat themselves, knew what was good for them, and what made them happy.

Lack of clarity as to the transition to management could be avoided by reassessing the condition often during the treatment process, talking and matching expectations over time and, most importantly, deciding together how and when to move into the long-term management phase.

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