

ORIGINAL RESEARCH

Comparing the experience of individuals with primary and secondary lymphoedema: A qualitative study



Ángela Río-González^a, Francisco Molina-Rueda^b, Domingo Palacios-Ceña^{c,*},
Isabel M^a Alguacil-Diego^b

^a School of Sport Science and Physical Therapy, Universidad Europea de Madrid, Villaviciosa de Odón, Madrid, Spain

^b Department of Physical Therapy, Occupational Therapy, Rehabilitation and Physical Medicine, Universidad Rey Juan Carlos, Alcorcón, Madrid, Spain

^c Department of Physical Therapy, Occupational Therapy, Rehabilitation and Physical Medicine, Research Group of Humanities and Qualitative Research in Health Science of Universidad Rey Juan Carlos (Hum&QRinHS), Universidad Rey Juan Carlos, Alcorcón, Madrid, Spain

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Abstract

Background: Lymphoedema is a chronic condition that has significant detrimental impact on patients' quality of life. Secondary lymphoedema often results from anti-tumour treatment, in contrast to primary lymphoedema which is the result of genetic abnormalities that leads to an abnormal development of the lymphatic system.

Objective: To describe and compare the experience of individuals with primary and secondary lymphoedema.

Methods: A total of 19 patients (mean \pm standard deviation age: 56.7 ± 16.2 years), 8 with primary and 11 with secondary lymphoedema, participated in this qualitative phenomenological study. Purposeful sampling method was applied. We recruited participants from specialised lymphoedema units of two physical therapy clinics and the Lymphoedema Patient Association in Spain. Data collection methods included unstructured and semi-structured interviews. An inductive thematic analysis was used.

Results: The findings suggest differences between the experience of living with primary or secondary lymphoedema. Also, those with lower extremity lymphoedema have more pain, fatigue, and functional limitations. Three primary themes emerged: "Emotional challenge", "Adapting your life to a new situation," and "lymphoedema management".

Conclusions: The experience of living with lymphoedema involves aspects of fear, suffering, coping, and management of the disease and differs between secondary and primary causes. However, it seems to be more dependent on its location than its cause.

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* Corresponding author at: Department of Physical Therapy, Occupational Therapy, Rehabilitation and Physical Medicine, Universidad Rey Juan Carlos, Avenida Atenas s/n, Alcorcón, Madrid CP 28922, Spain.

E-mail: domingo.palacios@urjc.es (D. Palacios-Ceña).

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Introduction

Lymphoedema is a volume increase in any part of the body, caused by an accumulation of protein-rich fluid and cellular debris in interstitial spaces, which can be multi-causal.¹ Lymphoedema is a chronic disorder, tends to be irreversible, and impacts patients' quality of life (QOL).² Secondary lymphoedema (SLE) is usually the result of anti-tumour treatment, with the main risk factors being surgery, lymphadenectomy, radiotherapy, and obesity.³ The incidence of secondary lymphoedema in women with breast cancer is 16–21%.⁴ In contrast, primary lymphoedema (PLE) is the result of genetic damage that leads to the abnormal development of the lymphatic system.⁵ It can affect the anatomy or lymphatic function and starts at any time from birth to adulthood.⁶

It is important to understand the impact that PLE and SLE has on the life of patients so as to identify the needs of those affected, along with the needs for society (families, health professionals, and legislators).⁷ Also, this information would help to understand the disease, its requirements, and improve clinical practice and adherence to rehabilitation programs. With a better qualitative understanding of the disease, physical therapists and the rest of the interdisciplinary team would better understand the experience of their patients, and how different types and location of lymphoedema affects QoL.⁷

People affected by lymphoedema often experience rejection, stigma, and discrimination. The resulting emotional consequences are known to impact QoL.⁸ However, the management of this condition has focused on prevention and treatment through drug administration, with scant attention paid to its real-life impact. Qualitative research (QR) and patients' narratives can provide a more holistic picture that may be more meaningful to practitioners.⁹ Qualitative methods are useful for understanding the beliefs, values, and motivations that underlie individual health behaviours.⁹ The majority of QR studies have focused on self-care, support needs, or social disclosure of patients with cancer-related lymphoedema.¹⁰ Few studies have focused on living with PLE.¹¹ Previous studies^{11,12} reported that people with PLE learn to adjust to daily demands of lymphoedema management. However, many continue to struggle with their self-esteem and lifestyle restrictions. Probably, there are differences in lymphoedema management, emotional challenges, or experiences. Therefore, further studies are required to illuminate the consequences of lymphoedema on people's lives according to the aetiology. Describing participants' perception of lymphoedema and establishing differences between those with SLE and PLE could help professionals and institutions to improve overall physical and psychological management of the patient. This study aimed to describe and compare the experience of individuals with primary and secondary lymphoedema.

Methods

The guidelines for conducting qualitative studies established by the *Consolidated Criteria for Reporting Qualitative Research*¹³ and the *Standards for Reporting*

*Qualitative Research*¹⁴ in health science were followed (<http://www.equator-network.org/>).

Design

A qualitative phenomenological study was conducted.^{15,16} In qualitative studies, phenomenology attempts to understand the essence of a phenomenon,^{9,17} and how individuals interpret their experiences. This experience always has a meaning for the person who has suffered it, and thus, phenomenological research uses first-person narratives from the participants themselves as a data source.^{9,17} In the present study, the phenomenon studied was "living with lymphoedema". This experience could have different meanings for people who had cancer-related lymphoedema compared to people who had non-cancer-related lymphoedema.

Research team

Four researchers participated in this study, including two physical therapists (ARG, FMR), one medical doctor (IMAD), and one research nurse (DPC). All researchers had experience in qualitative studies, and none had prior interaction with the study participants. Only one researcher (ARG) had prior clinical and research experience with people with lymphoedema. Prior to the study, the researchers established their beliefs and their experience for the research,^{9,15,16} and considered that lymphoedema produces multiple challenges for everyday life of individuals, and it can influence their social relationships and other aspects of daily life (eg, economic situation).

Context/Setting

In Spain, the public health-system generally provides patients with lymphoedema 15–20 sessions of complete decongestive therapy (CDT)¹⁸ per year and provides compression garment; for an annual cost of 2500 euros.¹⁹ In comparison, in private practice, the same 15–20 sessions of CDT are provided but patients are also followed weekly, monthly, and/or quarterly for maintenance treatment. This study was conducted at two physical therapy clinics with specialised lymphoedema units and patients were also recruited from the Lymphoedema Patient Association. Key clinical management aspects of lymphoedema include: evaluating clinical signs, classifying the stage of lymphoedema, controlling volume, understanding the pathology, learning how to handle the condition, and preventing risk factors.^{20–22} Lymphoedema daily care routine consists of myolymphokinetic exercises, skincare (hygiene and hydration), compression garment during the day, bandage or special night garment, and manual lymphatic drainage with physical therapists or self-drainage. Aerobic and strength exercise²³ and dietary guidelines apply mainly for patients with cancer.^{7,18}

Participants and sampling strategies

Nineteen patients participated in the study. All patients were recruited at their first visit to the unit, and an

interview was scheduled in the subsequent two weeks. Purposeful sampling was based on the relevance to the research question rather than clinical representation, and sampling continued until the data analysis produced redundant information.^{9,15,24}

Inclusion criteria for all participants were: a) 18–80 years old, b) a diagnosis of lymphoedema according to the volumetric difference with the contralateral limb classified as mild (less than 20% volume or 2–3 cm circumference difference measured with a flexible nonstretch tape),¹⁸ moderate (between 20 and 40% volume or 4–6 cm difference), or severe (more than 40% volume or more than 6 cm difference), c) at least stage 1 lymphedema, d) bilateral or unilateral, e) affecting upper or lower limbs. Additionally, for the PLE group, lymphoedema may have appeared at any time during their life and should not be related to cancer. While, for the SLE group, patients with gynaecological or urological cancer-related lymphoedema were included. The exclusion criteria consisted of: (1) the presence of lipodema, venous oedema, or dynamic oedema; (2) serious systemic and/or psychiatric disorders; and (3) inability to communicate in Spanish or sign the informed written consent.

Data collection

Data were collected between September 2015 and April 2016. Based on the phenomenological design, in-depth interviews (unstructured and semi-structured) were used. With the first 12 participants, an unstructured interview started with an open question: 'What is your experience with lymphoedema?'. Then, the researchers listened carefully, noted the keywords and topics identified in the patients' responses, and then used the participants' answers to ask additional questions and clarify the content of the answers.⁹ In this manner, relevant information was collected from the patients' perspective. An initial analysis of information was performed on the information gathered from the unstructured interviews of the first 12 participants. This analysis revealed relevant topics that required further study, thus requiring a second stage of data collection. This second stage, done with 7 participants, used semi-structured interviews based on a question guide (Table 1) that aimed to elicit further information regarding specific themes and topics of interest.^{9,15,24} In total, 19 in-depth interviews were conducted by AGR and FMR. Participant recruitment finished when there was repetition in the information obtained from the interviews.^{15,24} All interviews were tape-recorded.

Data analysis

First, a complete and literal transcription of each interview and the researchers' field notes was drafted. Subsequently, an inductive thematic analysis of the data was conducted by three researchers (ARG, FMR, DPC).^{24–26} Findings from qualitative data may be derived inductively—that is, obtained gradually from the data. This process began by pinpointing the most descriptive content to obtain meaningful units.^{24–26} Then, groups of meaningful units were created based on similar points or contents, allowing the emergence of topics (themes) describing the patients' experience. To identify

the relevant content, researchers read the data twice.^{9,25} In this manner, an increasing level of abstraction and complexity was established for the analysis from meaningful units to themes.^{9,25} This process of inductive analysis was conducted separately for each interview. Also, this process of analysis was conducted separately in interviews of the participants affected by PLE and SLE. In the end, a matrix was constructed with the integrated results from participants with both types of lymphoedema.²⁵ The results of the analysis were then combined during team meetings, in which the researchers met to discuss the data collection and analysis procedures.^{24–26} No qualitative data analysis software was used. Microsoft Excel (v. 2013) was used for descriptive statistics.

Rigour and ethical considerations

We used the criteria of Lincoln and Guba²⁸ (Table 2) to establish the trustworthiness of the data.^{9,27} The study was approved by the Rey Juan Carlos University Clinical Research Ethics Committee (protocol number: 180120160116) and performed following the Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments with humans.²⁹ Data were treated anonymously and confidentially. All the participants provided written informed consent.

Results

Nineteen patients with a mean age of 56.7 ± 16.2 years participated in the study. The majority ($n = 14$, 73%) were women, eight (42%) had PLE and 11 (58%) had SLE (Table 3). Three main themes were identified based on the experiences of patients with primary and secondary lymphoedema: "Emotional challenge", "Adapting your life to the new situation", and "lymphoedema management". Table 4 provides the results, alongside extracts of participants' quotes, to facilitate the traceability and their identification (Table 4).^{9,27}

We identified narratives from patients with primary lower limb lymphoedema (PLLL), primary upper limb lymphoedema (PULL), secondary lower limb lymphoedema (SLLL), and secondary upper limb lymphoedema (SULL). Also, the identified themes are shown as a summary of the results obtained by comparing the perspective of patients with PLE and SLE (Table 5).

Theme 1: "Emotional challenge"

The first theme is related to the psychological aspects of living with lymphoedema; patients deal with a constant psychological challenge. This theme contains two subthemes: bad feelings and facilitator elements.

Bad feelings are explained because life with lymphoedema is difficult, which leads patients to feel frustration, physical and psychological suffering, lack of understanding, and problems related to self-image or compression garments. A lack of understanding and empathy is the main characteristic described by the participants. Also, individuals with SLE have often undergone breast

Table 1 Semi-structured question guide.

Research topics	Questions asked
Experience with lymphoedema	What is your experience of having lymphoedema?
Emotional aspects	What did you feel when you heard of lymphoedema for the first time? How did you accept it? Were you afraid?
Information	What information would you like to have known at the beginning?
Daily reality	Do you feel limited in terms of quality of life? Do you dress in the clothes/shoes you want? How do you see yourself in terms of self-image?
Management and adherence	What information did you receive about prevention, management, infections, treatment? What do you consider important regarding lymphoedema? Why? Do you believe there is any relation between exercise and lymphoedema? What kind of treatment do you receive? How do you feel?

Table 2 Trustworthiness criteria.

Criteria	Techniques performed and application procedures
Credibility	Investigator triangulation: each interview was analysed by three researchers. Thereafter, team meetings were performed in which the analyses were compared, and categories were identified. Participant triangulation: the study included participants with different diagnoses. Thus, multiple perspectives were obtained with a common link (the experience of having lymphoedema). Triangulation of methods of data collection: unstructured and semi-structured interviews were conducted, and researcher field notes were retained. Participant validation: this consisted of asking the participants to confirm the data obtained at the stages of data collection and analysis.
Transferability	In-depth descriptions of the study were performed, providing details of the characteristics of researchers, participants, contexts, sampling strategies, and the data collection and analysis procedures.
Dependability	Audit by an external researcher: an external researcher assessed the study research protocol, focusing on aspects concerning the methods applied and study design.
Confirmability	Investigator triangulation, participant triangulation, data collection triangulation. Researcher reflexivity was encouraged via the performance of reflexive reports and by describing the rationale behind the study.

surgery, meaning that the scar is a constant reminder of their cancer. They may have not initially considered this issue important, being unaware that it has significance.

In contrast, patients with PLE feel that they are inequalities in the received treatment. They perceive that they have fewer rights and a lack of clinical care compared to those with SLE.

The participants narrate the following as facilitator elements: exercising in water, promoting an adequate healthy diet, performing physical therapy or rehabilitation treatments, and meeting someone who also has lymphoedema. The use of the internet as a consulting tool and new technologies sometimes help some patients, while for others, the lymphoedema images may be too shocking. Patients with PLE and SLE both commented that not overthinking lymphoedema helps them not to obsess and enables them to coexist with the condition.

Patients with SLE place a higher value on life after overcoming cancer for a long time. They tend to downplay this, but value the little things more intensely (eg, daily pleasures

that may normally go unnoticed). Being a survivor and being able to talk about it years later, as well as being healthy, generates a positive attitude in the present.

Theme 2: "Adapting your life to a new situation"

The second theme identified contains the following subthemes: uncertainty, acceptance, involvement, and responsibility. All interviewed patients understand the need to adapt and share the responsibility of improving their QoL, but all speak of difficulties with this task.

Uncertainty was cited because living with lymphoedema is similar to being on a roller coaster. Fear and doubts are related to volume increases, infections, and images on the internet. Almost all patients are afraid of the unknown related to this condition. Patients make mistakes due to lack of information about the problem at the onset of this disorder. Patients with PLE are afraid of worsening, mostly due to a volume increase and infections. Women fear pregnancy

Table 3 Sociodemographic data of the participants.

Patient	Age (years)	Sex / occupation	Type of lymphoedema / Body location	Live with	Duration of lymphoedema (years)	Aetiology	Duration receiving physical therapy (years)
P1	73	Female / retired	Secondary ULL	Husband	16	BC	14
P2	38	Female / dancer	Primary LLL	Boyfriend	6	Unknown	3
P3	43	Female / informatics	Secondary ULL	Alone	3	BC	1
P4	43	Male / architect	Primary LLL	Alone	20	Unknown	17
P5	71	Male / retired	Primary LLL	Wife	5	Unknown	5
P6	63	Female / pharmacist	Secondary ULL	Husband	18	BC	15
P7	77	Female / missionary	Secondary ULL	Friends	10	BC	9
P8	49	Male / commercial	Primary LLL	Wife and sons	20	Unknown	19
P9	57	Female / administrative	Secondary LLL	Alone	3	GC	1
P10	60	Female / early retirement	Secondary ULL	Husband	7	BC	6
P11	28	Female / lawyer	Primary LLL	Boyfriend	8	Unknown	3
P12	52	Female / housewife	Secondary LLL	Husband and sons	3.5	GC	2
P13	56	Female / administrative	Secondary ULL	Husband and sons	1.5	BC	1
P14	21	Female / student	Primary LLL	Parents and sister	1	Unknown	0.75
P15	68	Male / retired	Primary LLL	Wife and son	40	Unknown	19
P16	68	Female / retired	Secondary ULL	Alone	10	BC	0.67
P17	73	Male / architect	Secondary LLL	Wife and son	1	UC	0.5
P18	77	Female / retired	Primary LLL	Alone	40	Unknown	16
P19	62	Female / stewardess	Secondary ULL	Husband	2	BC	1

Note: BC, breast cancer; GC, gynaecological cancer; UC, urological cancer; ULL, upper limb lymphoedema; LLL, lower limb lymphoedema.

Table 4 Narratives of participants with lymphoedema.

Theme	Narratives
Theme 1: "Emotional challenge"	<p>A lack of understanding and empathy: "Lymphoedema grows and grows and you feel anxious. It started three years ago and it was horrible. I could not live with my life, I was misinformed and I got over it. You see that your life is not what you want. It is not pain, it is discomfort, like you have a volcano, with lava, it is the feeling you have in the summertime. If I take off the compression stocking it is a deadly itch, living with this is difficult" (P9, 57 yrs); "Doctors do not tell you that you can develop lymphoedema, they do not warn you. I put on bracelets, rings, lifted weight without control..." (P13, 56 yrs); "The beginning was not easy because the first doctors who treated me did not know what it was, they did not diagnose me despite doing a thousand tests. I had never heard of it, nor did I know what it was" (P15, 68 yrs).</p> <p>Suffer because of the chronicity: "Lymphoedema is worse than cancer. The cancer heals but the lymphoedema does not" (P6, 63 yrs).</p> <p>Generates a positive attitude in the present: "Lymphoedema is the price of being alive" (P10, 60 yrs).</p>
Theme 2: "Adapting your life to a new situation"	<p>Uncertainty and fear: "I am very afraid of having infections due to pain and because my lymph vessels are damaged, and that is a problem" (P6, 63 yrs); "Lymphoedema is more distressing than dealing with the diagnosis of cancer" (P17, 73 yrs).</p> <p>Lymphoedema implication/involvement: "I am better since I am more responsible, I do aquagym or swimming and the activities that my physio has recommended to me three or four times per week, pilates a few times and walking. I am improving because of that" (P11, 28 yrs).</p> <p>Differences between upper and lower limb lymphoedema: "It's not viable, I cannot stand without compression stockings, it's impossible. When I get out of bed, I wear them" (P2, 38 yrs); "There are days that I do not use the sleeve. If I do not wear it, it is because I am controlling it. If I see that it swells, I give myself more sessions of physio, and I use it more" (P13, 56 yrs).</p>
Theme 3: "Lymphoedema management"	<p>Information and specialists consulted: "I remember that it was a pilgrimage, first a doctor, then another doctor... then, the association against cancer, very different criteria among them" (P3, 43 yrs).</p> <p>Basic information: "Lymphoedema appeared in September 2008 after the summer, and I did not get diagnosed until June 2009, in orthopaedics by chance", "I went to several traumatologists and different doctors, and they could not diagnose it" (P2, 38 yrs); "My arm started to swell in the summer, I went to the hospital with anguish and they told me it was nothing. I think they did not know what it was" (P6, 63 yrs); "My hand swelled in the summer, and because I was on the beach, I thought I had been bitten by a bug. When I saw that it did not deflate, I searched for information on the internet" (P13, 56 yrs).</p> <p>Prevention: "I believe it is essential to prevent. If you leave a cancer operation with a sleeve and instructions to protect it, it is the best help recommendations they could do to help you. Whether or not you have the lymphoedema sequela" (P10, 60 yrs); "If you were warned, everything would be simpler. If the oncologist had told me at first, maybe I would have put the batteries: Surprisingly in a cancer hospital there is no lymphoedema unit, I hallucinate" (P12, 52 yrs).</p> <p>Rehabilitation, physical therapy, compression garments, and physical activity: "Thanks to being treated by very good physical therapists; my arm with lymphoedema diminished a lot" (P6, 63 yrs); "The surgeon's nurse told me to be patient, because you will have to do a lot of rehabilitation" (P7, 77 yrs); "My treatment to maintain the volume reduction is swimming, physio, bandages, pilates, and compression garments" (P9, 57 yrs); "After the intensive treatment I ordered the custom compression garment to complete it and maintain the reduction results" (P14, 21 yrs); "I believe that practice any sport is good for the head and for the body. Running and hydrotherapy are things that have made me feel much better, feeling less sick and more normal" (P3, 43 yrs).</p> <p>Diet and nutrition: "Now that I have just lost weight and my arm is better. I think some relationship has to exist between the lymphoedema and diet" (P3, 43 yrs); "I was referred to a doctor who treated the lymphoedema with nutrition and recommended that I take many natural foods, that I remove preserves, salted meats, fats...", "I followed a cleansing diet for three or four months, with enough vitamins, and that was a change for me, I noticed an improvement in agility with much less heaviness" (P4, 43 yrs); "I consider healthy food very important. When I have been underweight, my leg has been much better, that is clear" (P8, 49 yrs).</p>

Note: P, participant; yrs, years.

Table 5 Summary narratives of comparing living with primary and secondary lymphoedema.

Themes	Subthemes	Participants with primary lymphoedema	Participants with secondary lymphoedema
Emotional challenge	Bad feelings	Fear of lymphoedema getting worse (increased volume and infections).	Fear of cancer recurrence and reconstructive surgery in cases of breast cancer.
		Suffering from the possible evolution of lymphoedema during pregnancy.	Suffering from mastectomy and scars, and the constant memory of the past oncological process.
		Misunderstanding and frustration because they perceive differences in health care (treatment, priority of their needs).	
Adapting your life to a new situation	Uncertainty	Concern/ worry regarding the evolution of lymphoedema (progressive and constant increase in fibrosis and volume without treatment).	Concern /worry about the possibility of relating the appearance of lymphoedema with a worsening or recurrence of cancer.
	Acceptance	Take on limitations in quality of life, mainly patients with lower limb lymphoedema.	Difficulties to assume that when the cancer is over, something else appears, lymphoedema (they even say that lymphoedema is worse than cancer).
	Implication and responsibility	From their perspective, more involvement and adherence to treatment.	More responsibility in lower limb lymphoedema than upper limb lymphoedema.
Lymphoedema management	Prevention	They do not apply preventive measures because their appearance is unpredictable.	They perceive that they have not received adequate information regarding lymphoedema, risk factors, and preventive interventions. They are not involved in the decision-making process that would have largely prevented the impact of lymphoedema on their lives.
		There is clinical lack of knowledge about the disease, its origin, its evolution, and the appropriate indications for these patients. It is sometimes considered as an aesthetic problem.	
	Diagnosis	More time and difficulties to obtain it. Many different specialists visited. Many tests and most of them inconclusive.	Diagnosis easier and faster because the aetiology and risk factors are identifiable. They do not consider that the sequelae of lymphoedema is sufficiently valued.
	Treatment	Greater adherence to the compression garments in lower limb lymphoedema.	Patients with breast cancer related lymphoedema have less adherence to compression garments for aesthetic reasons, so that they are not seen (summer due to heat or important events).
		Perception that there is insufficient clinical assistance and rehabilitation professionals.	In some cases, they receive dietary guidelines related to the cancer process.
		Few indications on diet and therapeutic exercise. The patients highlight that infections recurrence is reduced with CDT.	

Note: CDT, complete decongestive therapy.

because of the lack of information about how it may impact their lymphoedema. In contrast, patients with SLE also have a fear of cancer recurrence and reconstructive surgery.

Lymphoedema is a chronic condition that usually requires lifelong management, and it is necessary to accept changes and acknowledge the new condition as soon as possible. The

longer the patients accept their lymphoedema, the more normalised is the situation. Patients pursue changes because of the diminished QoL. There are no differences described between patients with PLE and SLE; however, based on our data, patients with PLLL and SLLL have the worst QoL (compared to those with PULL and SULL) and typically have greater adherence to treatment.

Participants' narrations show how each person generates their maintenance strategies according to the knowledge of oneself and their own lymphoedema. Thus, participants with PLE narrate having more involvement than those with SLE. However, the real differences are between lymphoedema of the upper versus the lower limb because they are held more accountable and report more difficulties with compression garments; they cannot afford temporary lack of use of these garments.

Theme 3: "Lymphoedema management"

This theme has three subthemes: diagnosis, prevention, and treatment. Our participants explain that it is difficult to get a definitive diagnosis and that it is often necessary to visit many different specialists. Diagnostic results are delayed and not always conclusive. Also, for prevention, there are errors and previous information sometimes is inaccurate. All participants mentioned that there is generally poor information about the disease and consequently about an accurate diagnosis and early preventative care. Accurate information and additional specialists are needed. Basic information such as the influence of heat on lymphoedema is also often not provided to patients.

Patients with SLE do not understand why they had not been advised lymphoedema and its importance. They did not receive any early information about prevention or at least not at the right time. However, it is not clear when this information should be provided. Most patients agree that if they had been informed, they would have acted differently, and believe that it would have prevented many complications.

Both PLE and SLE groups consider it important to receive early treatment by rehabilitative doctors and specialised physical therapists, but this treatment is usually expensive. They recognise CDT as a practical approach to lessen the manifestations of lymphoedema and to reduce the recurrence of infections. Compression garments are an essential part of treatment (more important for lower limb lymphoedema). Physical activity and exercise is safe and recommended, and nutrition is important, but not all patients control their diet. Some patients with SLE may have dietary restrictions due to cancer.

Discussion

Our results showed that there were differences between the personal experiences of those with primary versus secondary lymphoedema in terms of psychological aspects of living with lymphoedema, the adaptation process to lymphoedema, and lymphoedema management. But, for both groups, the location of lymphoedema is also important with those with lower extremity lymphoedema reporting having more pain, fatigue, and functional limitations.

Patients with breast cancer-related lymphoedema suffer a greater psychological impact due to the treatment and uncertainty as a result of their oncology treatment.^{30–35} Patients with gynaecological cancer-related lymphoedema have additional *bad feelings* caused by the trauma associated with mastectomy, feelings of amputation, and changes in their body image, as well as the remaining scar and the memories associated with the process.

Patients have to accept these changes. A greater understanding of the condition, leads to increased acceptance, and a better experience. The relationship between pathology and the person is often summarised as: "the sooner you assume, the easier it gets". Our results are similar to those reported by Carter,³⁴ who stated that lymphoedema is more distressing than dealing with the diagnosis of cancer because participants must learn to adjust their lifestyle for the chronicity and daily attention required by lymphoedema. Regarding implications and responsibility, patients with lower limb lymphoedema (primary and secondary) have better adherence to the use of compression garments.

The more significant impact on QoL is seen for those with lower limb lymphoedema. They are most affected by pain and functional limitations due to limb volume, which is consistent with the results of several other studies.^{36,37} In patients with cancer-related lymphoedema, additional fatigue is reported due to chemotherapy. Cemal et al.³⁶ confirm that patients with cancer-related lymphoedema in their lower limbs are those that have a more significantly reduced QoL; our results agree with that conclusion. The review highlights the lack of adequate studies exploring health-related QoL in these patients.³⁶ It is noteworthy because lower limb lymphoedema is the most widespread worldwide, and it is considered one of the leading causes of disability in the world.

The physical therapist is the health professional who performs the CDT and probably the person who most closely shares the patient's experience.⁷ The complicated management of this pathology makes patients feel like they have no freedom. Lymphoedema is a chronic condition that usually requires lifelong management. The results demonstrate the need for changes in the management of lymphoedema to achieve adequate prevention, diagnosis, and physical therapy treatment, which are currently not effective.^{38,39} Similar conclusions have been previously reached by several authors.^{37,39–42} The participants demand CDT treatment and early diagnosis, with specialised physical therapist, and criticise the economic aspects. Prospective surveillance for lymphoedema has been shown to reduce the need for intensive rehabilitation and is cost-effective.¹⁹

Prevention with early physical therapy has shown to reduce the incidence of breast cancer-related lymphoedema.^{43,44} However, this information does not seem to have reached patients.³² In addition, there may be failures in the doctor-patient communication channel.⁴⁵ We observe differences between the perceptions of healthcare professionals and patients in this aspect. Patients with SLE mainly demand more and better information about their pathology, an aspect which was previously discussed in other studies.^{46–49}

The aspects related to the diagnostic subtheme are reported by 73% of the participants as an arduous and lengthy process. Patients with PLE waste more time obtain-

ing a diagnosis than those with SLE, affecting physical, emotional, and psychological aspects.

The results derived from the interview on treatment of lymphoedema cover everything related to specialised physical therapy, compression-containment garments, physical activity and exercise, food, and areas for improvement. CDT, performed by specialised physical therapists, is the most effective intervention procedure.^{50–53} According to patients, because those with cancer-related lymphoedema receive priority, there is inequalities in access to publicly-funded treatments. Several authors^{37–39} confirm that the care of and attention to patients with cancer-related lymphoedema is better than for non-oncological patients. Bogan et al.⁵³ suggest the need to understand non-cancer related lymphoedema to maximise adherence to treatment. It is necessary to maintain the limb with lymphoedema in good condition, which is difficult to achieve. There are few differences between PLE and SLE, with both groups using compression garments. Differences are primarily related to lymphoedema affecting the upper versus the lower limb. For patients with lower limb lymphoedema, patient adherence is higher because of the symptoms (pain and heaviness) resulting from lack of adherence. McNeely et al.⁵⁴ and Stuiver et al.⁴² have shown the effectiveness of compression garments. For patients with SLE, compression garments remind them of their cancer.⁴⁷

There is more evidence on the positive impact of *physical activity and exercise* for those with SLE.⁵⁵ Breast cancer-related lymphoedema is the most studied; however, properly monitored physical activity and exercise is recommended for all groups, both aerobic and strength training, on dry land or water immersion.^{23,56} While further studies are needed for the management of lower limb lymphoedema, recent data show that increased physical activity lowers the incidence and severity of the symptoms of lymphoedema.^{23,56,57} This also results in improvements in strength and function.

Almost all participants consider diet to be an important aspect of their rehabilitation because it can modify the lymphoedema state. Previous studies^{54,58} described the importance of diet and the relationship between obesity and lymphoedema. It is considered an essential element in their care, for which they seek advice and information.⁵⁴

Limitations

First, the qualitative nature of this study meant that the focus was on describing the experiences of the participants and, therefore, these findings cannot be generalised. Second, the experience reported here may also be related to the participant's age. For example, young people with PLE struggle with their self-esteem and lifestyle restrictions,¹⁴ and these aspects did not emerge in our results. Similarly, the themes that emerged from our sample, composed of both males and females, may differ from those studies that consider just one gender in their sample. Gender-related differences have already been reported to impact the personal experience related to several pathological conditions.^{59,60} Greenslade and House interviewed only women with lymphoedema and reported aspects that did not emerge in the current results; loneliness and huge sense of isolation.⁴⁷

Conclusions

There are differences in the experience of living with PLE and SLE regarding: a) the origin of fear and suffering, b) adaptation to pathology, and c) prevention, treatment, and diagnosis. Participants with PLE perceive lack of clinical care, while participants with SLE suffer a greater psychological impact. However, the experience of living with lymphoedema is more dependent on its location than on its cause, with those with lower extremity lymphoedema having more pain, fatigue, and functional limitations.

Conflicts of interest

The authors declare no conflicts of interest.

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