

An uncertain uphill battle – experiences and consequences of living with lipedema

Johan Dahlberg ^a, Elisabet Nylander ^a, Margareta Persson ^b and Alexander Shayesteh ^a

^aDepartment of Public Health and Clinical Medicine, Dermatology and Venereology, Umeå University, Umeå, Sweden; ^bDepartment of Nursing, Umeå University, Umeå, Sweden

ABSTRACT

Purpose: To describe and analyse experiences of living with lipedema. Methods: Individual, semi-structured interviews with a purposive sample of 12 women diagnosed with lipedema and analysed by qualitative content analysis utilizing an inductive approach.

Results: The overarching theme, “An uncertain uphill battle against a divergent body and societal ignorance”, covers the experiences of living with lipedema and is based on five categories; “Captivated by a disintegrating body”, “Face the impairments of a chronic condition”, “Experience social exclusion”, “Need emotional support to go on” and “Mull over an insecure future”. The women felt entrapped within their bodies and experienced social exclusion due to the chronic symptoms and the progressive body shape alteration caused by their illness. Having experienced deficient information on the illness, varying support from other people, and a deteriorating economic situation, the women face an uncertain future.

Conclusions: Symptoms and restrictions caused by lipedema affect women’s livelihood and future, as there are no indications for disease improvement. Preventive work aimed at reducing health deterioration should be a priority. More research is needed to raise healthcare awareness regarding difficulties experienced by patients with lipedema.

ARTICLE HISTORY

Received 24 April 2023

Accepted 25 December 2023

KEYWORDS

Lipedema; women; qualitative research; content analysis; body image

Introduction



Lipedema is a chronic disease characterized by a build-up of adipose tissue and was first described in 1940 (Allen, 1940). The prevalence of lipedema remains a contested issue. The disease almost exclusively manifests in women by increasing the volume and the number of adipocytes, mainly on the legs, but the arms may also be affected (Herbst, 2012). While the cause of lipedema remains unknown, a hereditary component has been suggested as part of the disease pathogenesis (Child et al., 2010). Lipedema usually has an onset associated with puberty, pregnancy, or menopause, contributing to an asymmetry of body parts, accompanied by symptoms such as pain and tenderness (Child et al., 2010; Reich-Schupke et al., 2017). Lipedema symptoms negatively impact daily life and are seldom improved by weight loss (Romeijn et al., 2018), while a study indicates improvement among women with simultaneous obesity after bariatric surgery (Fink et al., 2021). Quality of life in patients with lipedema is severely reduced (Dudek et al., 2021; Falck et al., 2022), and signs of depression have been reported in some affected individuals (Dudek et al., 2021).

There are often difficulties in differentiating lipedema from other diseases, for example, lymphoedema,

obesity, or Dercum’s disease (Forner-Cordero et al., 2012; Reich-Schupke et al., 2017). Hence, diagnosing lipedema is complicated due to a lack of consensus regarding criteria and a deficiency of specific patient assessment tools. Thus, clinicians are mainly restricted to the patient’s medical history and clinical findings from the physical examination. Nevertheless, published in the first Dutch guidelines (Halk & Damstra, 2017) is an extensive set of suggested criteria for diagnosing lipedema.

Due to a lack of scientific evidence, treatment options for lipedema are limited. Compression treatments, dietary recommendations, self-care (e.g., weight normalization, exercise, and skincare), and mental health support are common conservative treatments described in the literature (Bertsch et al., 2020; Halk & Damstra, 2017; Reich-Schupke et al., 2017; SBU, 2021). Surgical treatments, primarily liposuction, have been described as increasing the quality of life in patients by reducing pain and lipedema-associated symptoms (Baumgartner et al., 2021; Dadrás et al., 2017). However, the scientific evidence for liposuction as a treatment needs further research to evaluate this method (SBU, 2021).

Previous studies have shown that persons with lipedema experience feelings of being trapped in their bodies, are subjected to fat-shaming, and are

CONTACT Johan Dahlberg  johan.dahlberg@umu.se  Department of Public Health and Clinical Medicine, Dermatology and Venereology, Umeå University, Umeå SE-90186, Sweden

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viewed as lacking character (Melander et al., 2022). In addition, stigmatization from healthcare providers and the importance of social support has been described (Christoffersen & Tennfjord, 2023). However, these findings are based on informants with a self-described, not medically confirmed, lipedema diagnosis, which may have skewed the results and caused accuracy uncertainty.

Lipedema is a disease that is related to considerable disability and psychosocial distress for patients. Additionally, lipedema is largely unknown by the public and even among healthcare professionals, and research regarding many aspects of lipedema is warranted. In addition, investigating the experiences of living with lipedema is essential to understanding and becoming aware of how the disease affects individuals. Unfortunately, data regarding the experiences of women living with lipedema is scarce. Therefore, this study aimed to qualitatively investigate the experiences of living with lipedema in patients with a verified medical diagnosis.

Material and methods

Study design

We conducted semi-structured interviews with a purposive sample of women diagnosed with lipedema. The interviews were analysed by qualitative content analysis (Graneheim & Lundman, 2004) utilizing an inductive approach to understand the variation of descriptions in women's experiences and suggest further topics to investigate (Graneheim et al., 2017).

Recruitment and informants

Purposive sampling was implemented to gain information from a group of patients with lipedema, thereby increasing the study's rigour (Campbell et al., 2020). Primary health care general practitioners referred patients with suspected lipedema to specialist care at the Department of Dermatology and Venereology at the University Hospital of Northern Sweden. Fifty-four patients suspected of having lipedema were referred between 2019–2022, and all patients were diagnosed and managed by the same physician (JD). Twenty-four of these patients obtained a lipedema diagnosis. The diagnosis was set according to the criteria in the Dutch guidelines of lipedema (Halk & Damstra, 2017) and the original criteria by Wold et al (Wold et al., 1951). The twenty-four patients diagnosed with lipedema were further reviewed for a second opinion by two senior dermatovenereologists (AS and EN) for further verification regarding diagnosis. This procedure confirmed the medical diagnosis of all patients.

Table 1. Informant characteristics.

Female (n)	12
Age (years)	Median age 50,5 (IQR 16) Mean age 50,2 (\pm 11,2)
Lipedema stage (n)	
Stage 1	3
Stage 2	5
Stage 3	2
Stage 4	2

Inclusion criteria for this study were females with confirmed lipedema diagnosis, \geq 18 years of age, able to understand and speak Swedish, and onset of lipedema symptoms during puberty or later. Of the initial eligible twenty-four patients, ten were excluded due to: i) comorbidities creating ambiguities in what was represented by lipedema and not, and ii) inability to communicate in Swedish on a level necessary for an interview. This review process resulted in fourteen eligible participants who were contacted by mail and gave informed consent after obtaining information about the study. However, two of the eligible participants later declined without further explanation. A final sample of twelve women agreed to participate. The lipedema stage of the informants varied between stages 1 to 4, and the lipedema type varied among the informants with symptoms from arms, buttocks, thighs, and lower legs (Table 1).

Interviews

Based on the limited research and the clinical experience within the research team, an interview guide (S:1) was developed to probe important topics from the life of the informants. Examples of interview questions were "Can you describe your experiences of living with lipedema?" and "How has your diagnosis affected your work life?" as well as similar questions focusing on social life, personal relations, and activities. Follow-up questions, such as "Can you describe a situation?" and "Can you tell me more?" were used to illustrate the experiences further. Furthermore, long pauses were sometimes used to allow for contemplation and a natural flow of the interviews. After the fifth interview, collaborated by AS to increase interpersonal confirmability, questions were somewhat adjusted to gain more expressions of concrete situations and thoughts and to probe further into the intimate areas and conditions associated with shame. Data-source triangulation (Shenton, 2004) was performed as individual viewpoints and experiences were verified against other informants to obtain a rich picture of the attitudes, needs, and behaviours. At the end of the interview, an oral summary was conducted to enable the informant to add or clarify the information.

The first author (JD) performed all interviews. The first eight interviews were conducted in person in

a neutral conference room located separately from the clinic without any patient—caregiver associations or medical consultation. Due to the COVID-19 pandemic, the last four interviews were conducted as video calls, using Microsoft Teams® or Zoom®, depending on the informant's preference. All interviews lasted 50 to 90 minutes, were digitally recorded with the informant's permission, and were complemented with field notes. The audio files were then transcribed verbatim. JD made the first transcript, and two secretaries at the Department of Dermatology and Venereology, Umeå University Hospital, Sweden, made all other transcripts, which were checked for accuracy by JD. Although member checks were not performed with all informants, the four digital interview transcripts were sent to the informants. In some cases, minor misunderstandings were corrected or clarified.

Analysis

In qualitative content analysis, data and its interpretation are co-creations of the informant and the researcher, while the researcher creates further interpretation during analysis. Therefore, the text will be multilayered and have several meanings (Graneheim & Lundman, 2004). Thus, an inductive approach of qualitative content analysis addressing the manifest and latent meanings of the transcriptions was used to distill and enhance the understanding of data (Graneheim et al., 2017). The COREQ guidelines were used when documenting the study (Tong et al., 2007). Throughout the analysis, coding and emerging findings were repeatedly discussed within the research group, which consisted of researchers of different professional backgrounds and gender. All researchers had experiences performing similar studies or had received education on the subject.

First, the transcripts were read and reread several times, identifying content areas, and meaning units corresponding to the aim of this study. Next, these units were condensed to shorter text and labelled with codes, i.e., brief descriptions of the content. These were then sorted into sub-categories based on shared similarities defining a specific topic.

Finally, the emerging sub-categories were grouped into categories, and an overarching theme emerged. The theme, i.e., a thread of underlying meaning at an interpretive level running through the data (Graneheim & Lundman, 2004), is presented as a metaphor illustrating the overall narrative experiences of the informants. The emerging findings were discussed throughout the analysis among authors until consensus was established.

Ethical considerations

Ethical approval was obtained from the Swedish Ethical Review Authority, no. 2019–06344, and addendum no. 2021–01138. Before the interviews, all informants received oral and written information about the study and gave their oral and written consent to participate before the start of the interview.

Results

The theme that emerged from women's experiences living with lipedema was "An uncertain uphill battle against a divergent body and societal ignorance". Women described feeling entrapped by lipedema as they experienced a constant but failing struggle to alter the unwanted shape of their bodies. The negative experiences from lipedema affected daily life, and the lack of support, the feeling of social exclusion, and uncertainties about the future, resulted in an uphill battle being fought without a clear sight. Categories and related subcategories from women's experiences are summarized in Table II, and these are presented below with illustrative quotes from interviews.

Captivated by a disintegrating body

This category highlights the informants' experiences of lipedema as it affected their body image and contributed to being physically restricted and a sense of being held prisoner. While some problems caused by lipedema were manageable, others were not; hence, the outcome was to resign to the illness. The subcategories *Become increasingly aware of one's body image* and *Resign to the illness*, cover these aspects.

Table II. Theme, categories, and subcategories.

Subcategory	Category	Theme
Becoming increasingly aware of one's body image	Captivated by a disintegrating body	An uncertain uphill battle against a divergent body and societal ignorance
Resign to the illness		
Struggle with unfavourable physical symptoms	Face the impairments of a chronic condition	
Be limited compared to others		
Have strategies for adapting to the condition	Experience social exclusion	
Feel different and singled out		
Face disbelief and receiving negative comments	Need emotional support to go on	
Have shifting experiences of relations and intimacy		
Be acknowledged for having problems	Mull over an insecure future	
Act as a detective searching for information		
Tackle anxiety and worries due to progressive deterioration		

Become increasingly aware of one's body image

The informants' views and thoughts about their body shape were often expressed during the interviews. The most common association about lipedema made by the women, and also stated by others, was expressed as being fat. The informants also considered this association to cause them significant psychological burdens. The fear of receiving comments or being silently judged for their body shape was reported as a constant issue in some informants' minds. Thoughts regarding the disproportionate body image of lipedema had created disparaging self-images. Common descriptions and words reflecting this self-image used by the women were contemptuous, ugly, and disgusting. Furthermore, they expressed a feeling of being trapped in their bodies.

A large part of my view of myself has been that I am unsophisticated and simple. To be big and ungainly while others have viewed me small, have damaged my self-esteem and confidence as a woman. Participant #10

The body's size and shape were important as they could prevent activities such as airplane travel or trying clothes in public dressing rooms. In addition, activities that required that body parts could unintentionally be shown to others in public places or due to special events reminded the women of their illness and were avoided.

I would like to be in a swimming pool; however, I am afraid to take my clothes off as I do not dare to show my body to other people. Participant #7

Resign to the illness

Informants described that being unable to influence their body shape or the symptoms of lipedema was frustrating, and after several years they were forced to reconcile with their situation. While some did not shy away from showing parts of their body to others anymore, because of increased age or due to parenthood, others described accepting the shape of their body as a slow process. They could accept and manage their situation or constantly feel emotionally distressed by their looks. However, reconciling with their body shape and not feeling shame anymore was only described by some women.

One has to reconcile with and mourn what cannot be. Thus, accept the body that I have and what comes with it. Participant #12

Specific symptoms, for example pain, were described as a part of everyday life, and learning to live with these symptoms was necessary. This coping process was described as possible since

the exposure to some symptoms was slow and gradual. However, women described a difference in coping and accepting their situation concerning lipedema-associated problems, such as pain or heaviness, compared to the shape of their bodies. A reason given for this experience was that a symptom such as pain was more challenging to manage and accept.

It's a bit scary as one gets used to it; in the beginning, I consumed a lot of analgesics, but I don't anymore. The pain hasn't subsided, rather I believe I have a different threshold for it. Participant #5

Face the impairments of a chronic condition

The informants' physical symptoms were obstacles that permeated many aspects of life, such as causing an inability to work and resulting in financial problems. Despite this, physical adaptations and adjusting one's mindset to the situation were described as means to move forward. The subcategories *Struggle with unfavorable physical symptoms*, *Be limited compared to others*, and *Have strategies for adapting to the condition* further describe aspects of these experiences.

Struggle with unfavorable physical symptoms

Lipedema caused symptoms such as pain and feeling heavy in the extremities, which interfered with daily activities. The asymmetric and enlarged body shape created challenges in finding clothes that fit. Working and staying at the workplace required adaptations in the form of the women having to vary their body position or having their legs elevated to relieve pressure by putting them on a chair. Using an elevator in proximity instead of taking the stairs was necessary for transportation. Some women described limitations in walking due to a sensation of pain and their legs feeling heavy, which was exhausting. Some had experienced wounds and chafing on their legs due to exertion and uncomfortable body positions. Two of the participants even described having had thoughts of suicide to end the pain in their bodies.

I even considered death from this constant pain when it never subsided. It continued for 2–3 weeks, and I thought about going to Holland or something (to receive euthanasia) ... Having a life like this, no thank you. Participant #12

There was a significant variation between good and bad days as described by women in terms of symptoms. Although, some could not recall having had a so-called "good day", defined as feeling normal, relieved of symptoms, being able to move easier, doing things after work, or just leaving the house. In contrast, "bad days" were described as having

constant pain. On such a day, getting anything done was impossible; for some, even starting a washing machine would have been a success. As symptoms sometimes limited the ability to do basic housework, partners or spouses had to manage most of the daily household chores, which strained the relationship.

Then I have a bad conscience for my husband, who has to do everything despite working full-time and still has to do everything at home since I cannot help.
Participant #7

Be limited compared to others

The informants described being physically more limited than others due to lipedema. The pain from the extremities could cause them to abstain from activities with family members. Physical exercise and rehabilitation, necessary from a medical point of view, were challenging to attend to as there were additional needs to optimize analgesics and adapt equipment for participation. Activities like swimming, jogging, hiking, or going to the pub were not viable options due to pain and inability to move, creating a sense of exclusion. The feeling of exclusion was reinforced as friends and colleagues could wear attires that the women, due to their body shape, could not.

It is sad that you cannot participate the way you want. Especially when you want but you can't, that is because you do not dare or manage the physical challenge. Participant #4

Transportation was another challenge described by the informants; for example, sitting for a long time in a car or other means of transport would worsen the symptoms. In addition, the hindrance in driving a car by themselves, because of the body shape, created a dependency on a driver whenever they needed to get somewhere.

Alterations in work tasks, reducing work hours from full-time to part-time to cope, and forced sick leaves were reported, causing a change of occupation in some. In addition, the income reduction due to these work-related consequences caused a strained financial situation and, among some, even an accumulation of debt.

I can't work more because my body can't take it; hence, I will be in debt. I will be stuck in debt and won't be able to do things which makes me sad as my body is not cooperating. Participant #10

Have strategies for adapting to the condition

Women described various coping methods for adapting to the challenges lipedema created. Finding solutions to enable activities was a frequently described issue. For example, some suggested sewing unique bathing skirts, as it would make visits to the beach possible. Some had modified their clothes to accommodate the attire to the

shape of their bodies. Other informants exemplified alterations to equipment, making daily activities more straightforward, and acquiring aiding transportation methods, such as a walker or electric bike. Having insights about physical and social activities was important for women with lipedema, as this enabled them to cancel or withdraw if the activity could potentially cause a feeling of pain or discomfort.

Therefore, when I use my walker, I can walk farther than without. I can sit and rest for a while, then continue some more. It is good in that way. Participant #6

Some described how they previously had been in denial regarding their lipedema symptoms and, in some respect, still avoided speaking of it. Several women explained that they did not regret having children, despite the onset of their symptoms during pregnancy, and would make the same choice again. Some had decided that their symptoms should not hinder their daily life and that whatever activity they had started should be completed, with or without symptoms.

I am pretty stubborn and rather don't want to be restricted. So I keep fighting and try not to think about it (the lipedema). Participant #5

Experience social exclusion

Women with lipedema sometimes struggled with their body's appearance and felt misunderstood by other people, even by close family members. In addition, receiving negative comments or being made fun of by other women contributed to further efforts to hide and socially distance themselves from others. The subcategories *Feel different and singled out* and *Face disbelief and receive negative comments* describe these aspects.

Feel different and singled out

Women compared their body shape and impairments caused by lipedema with other women, friends, and family members in their community and the media. However, it was described that during puberty, the informants noticed that their bodies did not develop as their peers. Some women remarked that their childhood friends, who always had a similar body shape, length, and weight, suddenly became incomparable with them, especially around the thighs. The disproportionate body shape persisted into adulthood and was described as alienating women from the norm.

That it affects women and that you look overweight is a combination being met with the comment that you need to reduce your weight without taking the issue seriously. Participant #1

A common remark was that the shape of women appearing in television or magazines differed from the

informant's body shape. This was interpreted by women with lipedema as if they were different from the norm and not represented in the media. In addition, several women had experienced comments from their surrounding describing them as obese. Thus, the informants were careful not to participate in situations that made them a physical burden for others due to their body shape.

You hear repeatedly that you are not the norm or that you do not fit the norm. Participant #11

Face disbelief and receiving negative comments

Women with lipedema described managing the mental distress by keeping up a facade and avoiding speaking about their situation. For some, discussing lipedema with family members and their surroundings could result in distrust and bullying experiences. Among the informants, it was remarked that society often met them with suspicion and sometimes did not consider lipedema a disease but instead made up as an excuse by lazy, obese individuals. Also, women suffering from the early stages of lipedema, without extensive and visible changes on their bodies, could be disputed regarding the validity of their diagnosis by other women suffering from lipedema.

I find it shameful; it is difficult to undress when seeing a doctor or/and seeking healthcare. Their views are that you are fat, fat and lazy. Participant #10

Being in public spaces, such as stores and malls, could result in being met with grimaces, staring, judging comments, or gesticulates by others, parable to having a contagious disease.

One woman described being told by a family member that she was just fat and needed bariatric surgery. Finding support and acknowledgement was difficult for some, while other women expressed spiritual support, social media, and pets as positively affecting their mental health.

It has been a struggle with the family to make them understand. They have commented that I need to go out and move my body more while telling them that I have already done it, which is met with further comments questioning my determination. Participant # 7

Need emotional support to go on

Although some women had experienced a lack of understanding from others for the challenges in their life caused by lipedema, other women chose to remain open about these problems. In cases where women communicated with others about lipedema, it led to being acknowledged and receiving the support they wanted. These aspects are further described in the sub-categories, *Have shifting experiences of relations and intimacy* and *Be acknowledged for having problems*.

Have shifting experiences of relations and intimacy

Regarding intimacy and sexuality, some women described that lipedema created no hindrance regarding a relationship or being intimate with a partner, while others were restricted to varying degrees. Revealing the body's shape to a partner was a psychological challenge and difficult. In the physical act of sexual intimacy, pain, especially in some body positions and due to the women's physical constitution, was a negative interference. The pain was often described as associated with static and uncomfortable body positions.

In search for partners, women who avoided seeking relationships described not being comfortable enough with their bodies as a cause for doing so. If they would seek a romantic relationship, it would have been a challenge as they would have had to reveal their condition to a potential partner. However, women who informed their partners about having lipedema described this measure as improving their relationship.

Because of situations such as intimacy, I have difficulties letting others touch me or when someone is looking at me. It has created much suffering for me. Participant #8

Women in a relationship felt endorsed by their partners, who respected the limitation of their bodies and loved them regardless of their looks and shape. Although partner support and understanding were described as important, some women felt being a burden due to their illness, causing limitations in their partner's life. In the worst scenario, one informant described that lipedema had caused her to push away her husband and had contributed to their divorce.

Sometimes I have a bad conscience about restricting his life, that he cannot do as much as we did when we first met. Participant #7

Be acknowledged for having problems

To tell a friend, a colleague, or a family member about lipedema was described by some women as a positive emotional moment, with a feeling of relief. However, women found it difficult to discuss their problems during exacerbations of their illness, since they did not want to exhaust those entrusted. Overall, women confiding in other people regarding their condition reported being met with kindness, curiosity, support, or even shame because of how others previously had treated the informants.

It feels good to inform my friends and that they know. They followed my journey during my struggles, and

they feel that it is such a relief now that I have received a diagnosis. Participant #2

Family members and partners were described as sources of support as they were willing to listen and inquire about the informants' well-being. In addition, partners aiding with the physical and psychological challenges lipedema created in daily life were highlighted as important. Searching for support on social media, including joining Facebook groups and reading blogs, where women could interact and support each other, was also helpful. In addition, having friends, partners, and co-workers be aware of the condition and its associated problems increased the possibility of being acknowledged and supported.

Since I have been open about it, I have been able to get support, and I think it is essential to tell what you are going through so that friends understand that we can't go hiking or even go shopping with them today. Participant #12

Mull over an insecure future

The informants' uncertainties, caused by being affected by a generally unknown disease such as lipedema, made them search for information by joining social media groups or contacting patient associations, attempting to understand their symptoms further. While experiencing many pitfalls in their search for knowledge, the uncertainty about their future and the progression of the lipedema became worrying and difficult to manage. This is further elaborated in the subcategories *Act as a detective searching for information* and *Tackle anxiety and worries due to progressive deterioration*.

Act as a detective searching for information

Women described that they did not understand what was happening to them when the lipedema symptoms started. Some suspected having issues affecting their weight and sought healthcare but were not initially diagnosed with lipedema. Thoughts about being initially misdiagnosed or having other potential diagnoses considered were described. The obscurity and challenges of the illness continued to be a problem for women as the years passed. It was challenging to understand what was happening to their body and how they could stop the progression of the disease.

What has been cleared is that no one knows anything and that you must find everything yourself. Participant #11

Methods for obtaining information about lipedema varied among women. Some heard about lipedema for the first time on television; others read it in a newspaper or

magazine or even got information from a friend. It was uncommon for friends and family members to know about lipedema. Social media became a source of information for some women as several dedicated groups could be found online. However, the content on social media was not always helpful. The experience of social media groups with overly negative attitudes made some women reduce their commitment or directly avoid these forums. Other women described joining the Swedish Edema Association and learning more about their illness this way. Also, helping to spread information about lipedema to others was described as a way to reduce disease anonymity. Experiencing misinformation, ambiguous personal stories, and biased reporting was described as problematic as the information was not explicit for lipedema but could have been associated with other conditions. Also, the available information and images of lipedema on the internet were challenging to relate to, as some women considered themselves either too small or too large in body shape compared with others. Due to these reasons, women reported trying to maintain a source of criticism while searching for answers.

There is a lot out there that are peoples' own experiences. It is more difficult to find knowledge according to clinical-based evidence. You need to sift what makes sense and what doesn't. Participant #5

Tackle anxiety and worries due to progressive deterioration

The progressive nature of lipedema was a source of worrisome thoughts. Fear and uncertainty about being unable to continue working or using the attires women wanted were concerning. The advanced stages of lipedema were described as not being able to move and being confined to a wheelchair, further worsening of the body shape, and having an increase in pain which created fears for the future. In addition, women with lipedema had experienced a progressive alternation to the shape of their body as it had become bigger, more painful, and involved areas previously unaffected. This progressive change was reported to be associated with feelings of sadness, hopelessness, and self-pity.

Then, it is this emotional part, mostly sadness but also bitterness and anger regarding the situation resulting in me not being fun to hang out with, neither for others nor for myself. It is nearby in thoughts that everything is hopeless and useless and that I don't want to live a life like this. Participant #12

Although some women described having their symptoms improving or becoming more stable in time, they could not associate this change with any known cause. All women had some experience trying to improve their body shape with diets, exercise, and various treatments. But the lack of improvements

regarding body shape or the symptoms was frustrating as nothing helped, and they had no control over how lipedema changed their body. In some women, associating the onset of lipedema with pregnancy, there was a concern regarding their daughters being at risk of triggering lipedema because of pregnancy or hormonal changes.

I am terrified by everything that could trigger an exacerbation. I will soon be in menopause, and how will this affect me? It's so horrible, the thought of becoming worse. Participant #8

Discussion

This is, to our knowledge, the first study that has exclusively investigated the experiences of women living with lipedema who have been thoroughly examined and medically diagnosed. The theme that emerged, *An uncertain uphill battle against a divergent body and societal ignorance*, illustrated how lipedema made women feel captivated by a body without the possibility of changing its shape, while simultaneously experiencing social exclusion caused by either themselves or their surroundings. The difficulties in obtaining adequate and relevant information about lipedema, deficient support for their symptoms and well-being, and experiencing the negative impacts on their economy, all caused by lipedema, created uncertainty about the future and forced women to manage difficulties on several fronts in their life.

Diagnosing lipedema has been described as a challenge for clinicians as it shares some clinical features and symptoms with other diagnoses (Reich-Schupke et al., 2017; SBU, 2021). In our study, more than half of the patients suspected of having lipedema and referred to specialized care by their general practitioners were excluded for not fulfilling the used diagnostic criteria for lipedema (Halk & Damstra, 2017). Additionally, half of the patients diagnosed with lipedema were excluded for not being eligible according to the inclusion criteria of this study, mainly due to having several comorbidities, including overweight and obesity, which could have impacted our findings. While there has yet to be an international consensus for a specific definition or diagnosis criteria for lipedema in clinical praxis, more research is needed on many aspects of this disease. A remark is that previous studies investigating experiences of individuals with lipedema (Christoffersen & Tennfjord, 2023; Melander et al., 2022) had their research subjects recruited from patient associations or other sources without medical verification of their diagnosis. Although this sampling method could provide a general description of the experiences of a group of individuals, the bias caused by unverified, self-reported, diagnoses should be considered. Thus, such findings may be less specific for lipedema; hence they are more challenging to interpret.

Our study confirms previous knowledge regarding experiences from lipedema (Christoffersen & Tennfjord, 2023; Melander et al., 2022), such as having difficulties finding information about the disease, experiencing a lack of support from others, and suffering from an unchangeable and stigmatizing body shape. However, this study adds to the knowledge that women with lipedema experience economic burdens because of difficulties adapting to their work which causes them to stay home, take sick leaves, or eventually lose their occupations. As there is no data on economic burdens in lipedema, other studies have described the financial losses for patients with comparable and chronic conditions such as overweight and obesity (Hecker et al., 2022; Okunogbe et al., 2021). These studies report a considerable cost, burdening beyond healthcare and affecting society. It is, therefore, essential to educate and mentally support individuals with lipedema to reduce the risk for disease exacerbation and their following economic impacts. Furthermore, access to education and information about lipedema would facilitate a better understanding of the disease among patients and increase awareness in the general public for a healthy workplace.

Another important finding was that the informants' body image was described as a dynamic process. As the women became older, they were more accepting of themselves. This process affected their well-being and was also interpreted by us as positively affecting their partner relationship. Accepting and having a healthy view of body image affects the individual's judgement of their self-worth. However, a negative body image has also been associated with a higher risk for mental health conditions, such as eating disorders and depression (Grabe et al., 2008). In lipedema, this cycle of progressive fat accumulation disturbs the body's shape, associated with mental health issues (Dudek et al., 2021), and symptoms such as pain and heaviness are difficult to reverse as no curative treatment exists (SBU, 2021). In addition, women described uncertainties regarding their future as their bodies changed and the risk of exacerbating their symptoms increased. Therefore, a holistic approach, by preventing common co-morbidities such as obesity, diabetes, and diseases further restricting the physical abilities of patients (Falck et al., 2022), should be a priority for healthcare as it would not only improve the quality of life but also ease uncertainties about the future in patients with lipedema.

Strengths and limitations

Qualitative content analysis is a research method that analyses narrative data, often from a group of individuals. Data is obtained and produced by both researchers and informants within a context. Findings and conclusions yielded are subjected to

interpretation which could create challenges for transferability to a broader population. While the richness of data could be affected by talkative informants and their social context, the central phenomenon and obstacles experienced are often shared across languages and social barriers. Thus, this study's qualitative analysis provides valuable insights regarding difficulties experienced by women with lipedema.

The first author (JD) was the investigating physician who assessed the referred patients suspected of having lipedema. While it cannot be excluded that a physician-patient relationship could have affected the descriptions provided by the informants during the interviews, the knowledge and understanding gained by JD from clinically assessing individuals with lipedema broadened the aspects of the questions used in the interviews. Furthermore, as there are no treatments subsidized by the Swedish healthcare system for lipedema, no promise of treatment options was offered, and no future contact regarding their care was planned with the informants.

Conclusion

Lipedema creates an unhealthy self-image in women, restricting social interactions and captivating them in their bodies. Symptoms and physical restrictions caused by lipedema affect women's livelihood and future as there are no indications for disease improvement. Therefore, preventive work aimed at reducing health deterioration should be a priority. More research is needed to raise healthcare awareness regarding difficulties experienced by patients with lipedema.

Acknowledgments

We want to thank all women who shared their experiences and the medical secretaries at the department for their help transcribing the interviews.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The work was supported by the county council of Västerbotten, Sweden, and the Swedish Lipedema Foundation.

Notes on contributors

Johan Dahlberg (JD), MD., and Ph.D.-candidate at the Department of Public Health and Clinical Medicine, Dermatology and Venereology, Umeå University, Sweden. He conducts his research in the field of lipedema.

Elisabet Nylander (EN), MD., Ph.D. and professor at the Department of Public Health, and Clinical Medicine,

Dermatology and Venereology, Umeå University, Sweden, and her research addresses topics concerning sexually transmitted diseases, genital dermatosis, and lipedema.

Margareta Persson RNM, Ph.D. and associate professor in Reproductive and Perinatal Health at the Department of Nursing, Umeå University, Sweden, and her research addresses topics concerning women's health.

Alexander Shayesteh (AS), MD., Ph.D. at the Department of Public Health and Clinical Medicine, Dermatology and Venereology, Umeå University, Sweden. He conducts research in primary hyperhidrosis and lipedema.

Availability of data and material

The data that support the findings of this study are available from the corresponding author, JD, upon reasonable request.

ORCID

Johan Dahlberg  <http://orcid.org/0009-0003-9204-1474>

Elisabet Nylander  <http://orcid.org/0000-0001-6009-6911>

Margareta Persson  <http://orcid.org/0000-0002-5300-0990>

Alexander Shayesteh  <http://orcid.org/0000-0003-0700-7195>

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