

Struggles in Accessing Healthcare, the Experiences Made by Women with Lipedema in Sweden – A Qualitative Study

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Background: Lipedema is a relatively unknown condition, often leading to misdiagnosis and a lack of proper treatment.

Purpose: To explore the experiences of seeking healthcare support and treatment among women with a physician-verified diagnosis of lipedema.

Methods: Twelve women with lipedema, verified by medical examination, were interviewed using semi-structured interviews. The transcribed data was analyzed using qualitative content analysis with an inductive approach and abstracted to visualize manifest and latent meanings.

Results: The theme “Pushing the barricaded doors to treatment and care while fighting to illuminate the shadows of lipedema” describes the experiences of women being denied subsidized treatment and disregarded by healthcare professionals. The theme is based on three categories “Experiencing societal injustice and gatekeeping in healthcare services”, “Combating prejudice and stigmatization with increased awareness”, and “Having a solid desire for improved and affordable treatment options”. Women with lipedema described feelings of being abandoned by decision-makers and healthcare. When in need of symptom relief, women with lipedema searched and attempted different therapies, and when treatment were available, the women would have to pay for it themselves.

Conclusion: Lipedema remains an unknown disease with few available treatments in subsidized healthcare. Lack of experience regarding lipedema among healthcare professionals and their failure to assess the condition risks damaging the confidence of affected women. Therefore, increased awareness and education of healthcare personnel to increase the clinical recognition of lipedema are necessary first steps to reducing misdiagnosis, improve patient satisfaction, and the availability of care among patients with lipedema.

Keywords: content analysis, women's health, treatment availability, patient experience

Introduction

Lipedema is a chronic and progressive disease manifested by an accumulation of adipose tissue.¹ The cause of lipedema remains unknown, but a hereditary component has been suggested as part of the pathophysiology.² While an accurate prevalence remains unknown, it has been estimated to affect up to 10% of the population.³ Women are almost exclusively affected, and lipedema manifests itself by thickening the adipose tissue on the lower extremities, initiated during puberty, pregnancy, or menopause.⁴ Symptoms of lipedema consist of pain, tenderness, and hematomas in the affected limbs.^{2,3}

While attempts have been made to establish diagnostic criteria for lipedema,⁴⁻⁶ no consensus or internationally agreed-upon criteria for the disease exist. Thus, clinicians are restricted to assessing patients' medical history and clinical findings. Hence, misdiagnosis of lipedema with diseases such as lymphoedema, Dercum's disease, or obesity is common^{3,7} and causes delays in care and treatment.⁸ A study by Christoffersen & Tennfjord⁹ reported that patients with lipedema often experience misconceptions, such as being labelled lazy and obese, but also being met with disrespect when interacting with healthcare providers. Similar findings were described by Melander et al,¹⁰ reporting that patients

experienced becoming laboratory specimens, only suitable for examination, but seldom given a diagnosis. Furthermore, experiencing prejudiced comments about one's weight and being questioned by healthcare professionals have been described as harming the mental well-being of lipedema patients.^{9,10}

Medical treatment of lipedema consists of weight management, aimed at preventing further weight gain since obesity could worsen the symptoms,^{5,11} and compression therapy by garments or different forms of manual lymphatic drainage (MLD), aimed at decreasing tissue inflammation.^{3,11,12} Surgical treatments consist of liposuction combined with post-surgical decongestive therapy to remove the affected tissue,^{13,14} and bariatric surgery meant as a weight-reducing procedure.¹⁵

In lipedema, challenges regarding diagnostic criteria often result in misdiagnosed patients and, consequently, difficulties getting access to needed care and treatment. Only a few qualitative studies have highlighted the situation of affected patients. There is a clear discrepancy between patient expectations and the role of healthcare in management and recognition of lipedema.

Thus, this study aimed to explore the experiences of seeking healthcare support and treatment among women with a physician-verified diagnosis of lipedema, as it would enable healthcare services to improve the management of this group of patients.

Materials and Methods

Study Design

This exploratory qualitative study used an inductive semi-structured interview design comprising individual interviews.

Setting and Procedure

The procedure of this study and its interview guide have been described in detail elsewhere in a previous publication covering women's experiences of living with lipedema.¹⁶ A purposive sample of twelve women with lipedema, referred by primary healthcare to the Department of Dermatology and Venereology at the University Hospital, Umeå, were recruited to the interview study between 20/4/2020 and 31/1/2022. All women were medically assessed regarding the lipedema diagnosis according to the suggested criteria by Wold et al and Halk & Damstra.^{5,6} The inclusion criteria were females with a lipedema diagnosis, >18 years of age, able to understand and speak Swedish, and onset of lipedema symptoms during puberty or later. Exclusion were due to i) comorbidities clouding what was caused by lipedema and ii) inability to communicate Swedish at a level necessary for an interview. A total of 14 eligible informants were identified and contacted with information regarding the study, two declined participation without further explanation, and twelve gave informed consent.

Data Collection

An interview guide ([Supplementary Figure:1](#). Interview-guide) was developed, based on the team's clinical expertise and literature, regarding healthcare experiences, and was used as support during the interviews. The interviews focused on the participants' experiences of treatment, support, and interaction with healthcare professionals. Additional probing or follow-up questions were asked to clarify and deepen the participants' responses. Long pauses were used to allow for contemplation. The first author (JD, male MD specializing in dermatology and venereology) conducted all interviews, of which eight were performed face-to-face, and the last four interviews were performed via Microsoft Teams or Zoom due to the COVID-19 pandemic. All interviews were digitally recorded, and memos were also written during the interviews. After the fifth interview, which was collaborated with AS to increase interpersonal confirmability, the interview guide was slightly refined to gain examples of more concrete situations. Data-source triangulation¹⁷ was carried out by verifying individuals' descriptions and experiences against other participants to obtain an extensive view of the informants' experiences, viewpoints, and needs. All interviews were concluded with an oral review of the topics discussed, enabling the informant to add or clarify the information obtained. Except for the initial interview, transcribed by JD, the transcripts were made by medical secretaries at the clinic. A detailed description of the interview procedure is presented elsewhere.¹⁶

Analysis

The transcribed interviews were analyzed using inductive manifest and latent content analysis.^{18,19} The analysis was conducted manually and was initially performed in Swedish. However, as the analysis progressed, English was used, and translations of the developing subcategories, categories, and theme were applied and discussed for translation accuracy. Using an inductive approach, the verbatim transcribed data were successively abstracted stepwise to visualize the texts' manifest and latent meanings.¹⁹

More precisely, the stepwise analysis consisted of re-reading the transcripts several times while content areas were identified and divided into meaning units. The meaning units were condensed and labelled with codes. Codes with similar meanings were grouped into subcategories and further abstracted into categories. Several alterations to the emerging categories were made within the research group and discussed to reach a consensus. After that, categories were discussed to identify a potential overarching theme illustrating the latent meaning of the participants' experiences with healthcare services. The theme comprises the essence of the participants' experiences as shown in codes, subcategories, and categories, and can be presented as a metaphor.¹⁹ Throughout the analysis, emerging findings were discussed repeatedly within the research group to secure a solid interpretation. One theme and three categories were identified in our analysis.

Rigor

In qualitative research, trustworthiness is an important area to address, as subjective interpretations are always present. While interaction between researchers and informants creates data, a reflective approach is essential for assessing the subjectivity and the influence of context on the research process. A continuous discussion of methods, analysis, and interpretation of data within the research group, consisting of researchers of different genders, ages, and professional backgrounds, ensured aligning decisions during the various phases of this study.^{17,19} Purposive sampling was used to obtain appropriate and relevant information from a selected group of persons diagnosed with lipedema, thereby increasing the rigor of the study.²⁰ Further ensuring the credibility of this study, quotes from the participants strengthen the findings.¹⁸ While member checks¹⁷ were not conducted with all participants, the transcripts from the final four interviews were sent to the corresponding participants, and minor clarifying adjustments were made, such as the name of a physical training program used by one participant.

Results

A total of 12 women participated in this study, all with verified lipedema, and the characteristics are described in [Table 1](#).

Table 1 Participant Characteristics Presented on a Group Level

Women (n)	12
Age, median (years)	50.5 (33–74)
Lipedema stage (n)	
Stage 1	3
Stage 2	5
Stage 3	2
Stage 4	2
Occupation (n)	
Light physical work	3
Heavy physical work	4
Unemployed*	5

Note: *Unemployed, including retired or on sick leave.

The emerging theme “Pushing the barricaded doors to treatment and care while fighting to illuminate the shadows of lipedema” describes experiences of women regarding an unjust system, experiencing gatekeeping from policies and prejudice from healthcare personnel preventing them from finding care. The experiences were double-faced. On one hand, women were fighting for access to care and treatment within healthcare services, and on the other hand, they struggled to illuminate the ignorance of lipedema. An overview of the findings is summarized in Table 2, and the three categories and corresponding subcategories are presented below with descriptive quotes from the interviews.

Experiencing Societal Injustice and Gatekeeping in Healthcare Services

This category highlights the informants’ experiences of societal inequality due to a lack of support and suggested changes that may improve a faulty system. The subcategories *Experience societal inequality and a lack of support*, together with *Hoping for changes in an imperfect system*, further describe these experiences.

Experience Societal Inequality and a Lack of Support

Throughout the interviews, women described varying experiences of feeling unfairly treated or unprioritized by healthcare professionals. A diagnosis of lipedema did not mean receiving adequate treatment. The recurring response from healthcare professionals was that the disease did not subsidize conservative and surgical treatments. If women with lipedema wanted treatment, they were told to finance it by themselves. Furthermore, the participants pointed out that women with other diagnoses, such as lymphoedema or follow-up care for cancer, had access to a wide range of conservative or surgical treatments, but they were denied treatment options. Women with lipedema reported a sense of grief at being denied these treatments and experienced unfair and avoidable differences in healthcare.

There are many diseases where you get excellent care from healthcare, why won't I receive the same, I also have a diagnosis and a disease Participant #1

Another remark was that access to treatment could also depend on the place of residency. Women in remote areas who considered financing their treatment due to a lack of healthcare options, such as private clinics, had significant problems finding a healthcare provider. This issue amplified the feelings of unfairness and inequalities in healthcare services. Decisions to deny treatments by healthcare professionals were motivated by a lack of evidence regarding various treatment options. In addition, the perceived lack of financial support for research and private healthcare clinics aimed

Table 2 An Overview of the Findings Presented as Subcategories, Categories, and Theme

Subcategories	Categories	Theme
Experience societal inequality and a lack of support	Experiencing societal injustice and gatekeeping in healthcare services	Pushing the barricaded doors to treatment and care while fighting to illuminate the shadows of lipedema
Hoping for changes in an imperfect system		
Search for an explanation of the disease	Combating prejudice and stigmatization with increased awareness	
Face disbelief from healthcare professionals		
Restricted access due to treatment-related costs	Having a solid desire for improved and affordable treatment options	
Attempt to improve symptoms with conservative treatments		
Experience ambiguity regarding surgery and fears of complications		
Test alternative therapies		

at improving care for women with lipedema was felt as being disregarded. As women questioned the reasons for deficient financial support, politicians and other decision-makers were often perceived as unavailable and seldom replied to their inquiries. In addition, while some healthcare professionals did not support state-subsidized treatments such as liposuctions, they conducted this treatment in private clinics, fully charging the patients. Thus, limitations in getting the required treatments were described as a matter of financial and social class, only affordable by a select few.

I consider it wrong that they should make money from our situation, they charge several hundred thousand [Swedish krona]. It feels horrendous as principle, you shouldn't have to pay for it (liposuction) yourself, but have it financed by the social healthcare system Participant #6

Hoping for Changes in an Imperfect System

Having experienced limitations in the healthcare system and the care provided, the women suggested improvements based on examples of the few situations when care had been good and satisfactory. When probing how healthcare professionals could better identify patients who unknowingly have lipedema, women suggested selective screening during certain healthcare visits. Their suggestions included midwives, school nurses, or physiotherapists, which could increase the possibility of finding lipedema at an early stage and preventing progression. However, when the suggestions from the initial interviews were given as examples to the participants in the later interviews, their opinions deviated, as suggestions of screening by maternal care were seen as intrusive when pregnant and not actively seeking care. The mostly agreed-upon screening situation perceived by the participants, although not unanimous, would be by primary care physicians in the same way that they screen for alcohol abuse or smoking.

It [screening for lipedema] could be done by a routine check somehow. That it is a part of the visit, just like questions regarding alcohol and tobacco Participant #1

Having primary care physicians perform screening for lipedema raised problems, as the women's experiences were that most primary care physicians were unfamiliar with lipedema and would not recognize it. Having spoken to friends and relatives working as healthcare professionals, the women discovered that lipedema was unknown and not taught at medical school. Remedying this was highly suggested, as well as increasing awareness among those already working within healthcare. Frequently, visits to healthcare seeking help with symptoms, without receiving a diagnosis or treatment, were described as frustrating. This also made the women wonder if an early diagnosis would have changed the disease progression. While most participants' interactions with healthcare were described as dissatisfactory or outright demeaning, the few positive ones were raised as aspirational goals. Healthcare providers with knowledge of lipedema, who had suggestions on where to direct referrals or treatments for the women to attempt, were highly regarded by the women. Being able to have a serious discussion with a physician concerning symptoms and feeling heard was perceived as a big step in the right direction.

The temporary doctor was the best because he had a theory, and it felt so good that he had an idea about what was wrong Participant #11

Combating Prejudice and Stigmatization with Increased Awareness

Women reported being met with disbelief regarding their symptoms and were often dismissed by healthcare professionals who considered them obese. Since finding acknowledgement for lipedema symptoms was not experienced in healthcare services, other sources of acknowledgement and explanation were sought. The subcategories Search for an explanation of the disease and Face disbelief from healthcare professionals further describe these experiences.

Search for an Explanation of the Disease

The information and medical support from healthcare were described as mostly insufficient or non-existent, as women had to look elsewhere for answers regarding lipedema. Close family, such as mothers, sisters, or daughters, were sources of information and knowledge. The female family members were found to share similar stories regarding disease triggers responsible for the onset or worsening of lipedema symptoms. These experiences were described as related to events

such as puberty, pregnancy, or menopause, but also included high-dose hormonal treatments and traditional low-calorie diets affecting lipedema onset and symptom exacerbation. An emotional description given by one of the participants regarding information achieved from healthcare was when her daughter was advised to avoid further pregnancies, as it could potentially cause the lipedema symptoms to worsen.

She (daughter) has two children, and the lymph therapist advised against having more children. It's tough, she had wanted more [children], but she said; 'Then it is very likely that you will become worse. Since it is a hormonal disease, it tends to flare during pregnancy and become worse and worse. It's sad for her, and it's sad for me [not to get more grandchildren] Participant #3

The reactions to receiving a diagnosis were described initially as a relief. This facilitated and simplified the task of searching for further information about lipedema and confirming women's concerns about their symptoms not being linked to self-inflicted conditions, such as laziness, obesity, or simply being abnormal. However, the relief of having a diagnosis was described as not long-lasting, as information about treatment options for lipedema was the next hurdle experienced. The situation was described as, instead of understanding the underlying causes of the issues, women found themselves with a chronic condition for which no assistance was available.

You get a chronic condition but nothing to be done for it; it feels horrific to tell that to someone Participant #8

Face Disbelief from Healthcare Professionals

Women often recounted being questioned or dismissed when presenting symptoms associated with lipedema during interactions with healthcare providers. Regardless of their symptoms, the focus during a consultation would frequently revolve around their weight and healthcare professionals' weight loss recommendations. Women described situations where they were told that nothing was medically wrong with them, all health-related tests were normal, the symptoms were just in their heads, and they had caused their health problems themselves. In some cases, when women consulted healthcare and complained of symptoms such as pain or asked if they could suffer from lipedema, after a quick examination, the physician would declare that they were just obese and needed to lose weight.

I have felt that I don't get any acknowledgement when I have seen a doctor. They take a quick look and "No, this is obesity... can't do anything" Participant #5

Apart from the experiences of facing dismissal and being categorized as obese, some women also described having experienced demeaning and degrading behavior from medical professionals, such as being met with laughter by a physician during a physical examination of the legs. Women also recounted instances where certain physicians seemed to fabricate excuses for withholding treatment for lipedema. One participant shared her experience of being called to a meeting only to be informed that she would not receive assistance. The skepticism and lack of support from healthcare professionals and the healthcare system led these women to develop a negative perception of seeking medical help. This made them seek information and relief from alternative sources for their symptoms.

The doctor, he laughed when he saw my legs. I thought, 'He must be crazy; he must be crazy!'. I was neither angry nor sad; I think I was just so shocked Participant #2

Having a Solid Desire for Improved and Affordable Treatment Options

Women with lipedema revealed having limitations in treatment options due to their financial situations. Despite this, conservative treatments were attempted with various successes, while surgery, both bariatric surgery and liposuction, was explored as a possible therapeutic option. Additional treatments outside traditional healthcare were explored, hoping to find the treatment that would relieve their symptoms. This is further described in the subcategories Restricted access due to treatment-related costs, Attempt to improve symptoms with conservative treatments, Experience ambiguity regarding surgery and fears of complications, and Test alternative therapies.

Restricted Access Due to Treatment-Related Costs

As negative experiences from state-subsidized healthcare forced some women to turn to private healthcare, they had to cover treatment expenses themselves. The treatment options available in private care were reported to vary in quality and extent. Acquiring compression garments was a limited treatment option since the garments were worn out quickly and meant high long-term expenses. Similarly, many women expressed a wish to use manual lymphatic drainage (MLD) treatment, either by a therapist or by a machine. Undergoing MLD sessions with a therapist necessitated ongoing treatments, leading to significant costs and rendering it an impractical option. This approach became even more complicated when the provider was far away, requiring additional travel to access treatment. Although using a machine for MLD might result in lower expenses over time, the initial cost was prohibitively high and deemed unaffordable.

I can't afford to go to see a specialist in Stockholm (capital of Sweden) either. It is hard to get help, hard even to begin to get help Participant #4

Liposuction was described as the most desired treatment and a potential solution to the symptoms. However, since treatment had to be financed by women out of pocket, it was not considered affordable by most. When discussing the expenses associated with liposuction, it encompassed not only the procedure itself but also transportation to and from the treatment facility, as well as post-operative care. Moreover, women noted that achieving the desired effect often required multiple surgeries, leading to additional costs. Since the tax-funded healthcare covered neither liposuction nor the MLD expenses, the combined price of each treatment posed the primary barrier to pursuing further treatments. It was also highlighted that while women felt supported by their partners in undergoing various treatment procedures, their households lacked the necessary financial resources to cover the associated expenses.

I think he [partner] is very frustrated that I don't get help. He finds it very frustrating. I believe that he, more than myself, has felt that it is demanding that we, for example, can't afford to go and get liposuction Participant #5

Attempt to Improve Symptoms with Conservative Treatments

Attempting to improve lipedema-caused symptoms, women described using various conservative treatments suggested by international recommendations and information sometimes obtained from healthcare. The experiences of conservative treatments encompassed compression garments, such as pants and sleeves, massage therapies, and MLD. The experiences from conservative treatments varied greatly, as it was beneficial for some but ineffective or even worsened the symptoms in other women. Compression garments were described as helpful, and daily use increased the stability of the limbs, thus enabling increased activity for women. For certain women, the garments exacerbated pain sensations in their lower limbs, even after trying different sizes. These challenges in wearing the garments were so significant that they avoided using them altogether.

I am so sick of compression garments; I don't know how I will manage to live the rest of my life with them; I'm sick of them. But they have helped Participant #1

Finding a type of compression garment with a desirable design was reported as an important factor. Garments developed for other conditions, like lymphoedema or oedema caused by chronic venous insufficiency, were experienced as having too much compressive strength, making them impossible to wear, hence failing to improve the symptoms. Similarly, massage therapy and MLD were reported to have had a variation in effect; therapists applying a method of intense treatment could potentially increase the pain, while a gentle approach could fail to generate improvement. Among those who had tried MLD, some described it as beneficial and improving their symptoms, mainly due to reduced swelling and pain in the limbs. Other women described no improvement by MLD and subsequently chose not to attempt the treatment again.

It feels like it dissolved, and you became softer in the legs. That's what lymphatic massage should do, softening the legs so the fluid can pour through Participant #6

Experience Ambiguity Regarding Surgery and Fears of Complications

When surgical treatments were discussed, women raised two different methods: bariatric surgery and liposuction. Thoughts regarding bariatric surgery were described from either the perspective of those who had undergone the procedure or as women contemplating undergoing the treatment. Women who had undergone bariatric surgery described either obtaining a modest decrease in weight first but later regaining the lost weight and having to do new surgeries, or obtaining a prominent asymmetry between the upper and the lower part of their body after the surgery. The latter was further elaborated as parts of their body, eg their thighs and hips, being the same size as before the surgery, while the rest had shrunk. Women regarded this body image as unhealthy in terms of appearance.

When you have a size 34 on top, and you have a 40 above the butt, you do not look healthy participant #2

Only two women had experienced liposuction as a treatment for lipedema. Because of complications involving post-operative infections and inadequate follow-up care, one individual opted out of pursuing additional liposuction sessions. Another woman desired further surgeries but was hindered by her financial circumstances. Both women mentioned experiencing tissue re-growth in the treated areas, but the woman who desired further surgeries had noted improvement in pain reduction. The thought of liposuction was met with different attitudes among the women who did not have personal experience with the treatment. The women who were hesitant about liposuction described their perspective on it as a treatment with potential risks and requiring an extended period of post-operative care. The participants who sought liposuction thought it would be a solution to their problems and the only possible way forward. They had heard from other patients with lipedema who had undergone treatment and experienced positive effects. These women argued that since the treatment showed promising results in other countries, it should be included in subsidized healthcare.

Ten years later, the pain would still be much less than before, after they have taken out the lipedema fat cells, they have a more active and enriching life. I hope it will be possible to get liposuction Participant #3

Test Alternative Therapies

Women who did not adhere to recommended treatments by healthcare looked for alternative sources for information regarding the amelioration of their symptoms. These sources were social media platforms and online videos containing information about treatments to reduce edema, mainly in the form of self-administered lymphatic drainage, known as “Angel-wings” or “Dry-brushing”. These treatments were described as mobilizing liquid in the extremities and moving it towards the center of the body. Women who had tried this method reported obtaining mixed results but no lasting change in their lipedema.

To me, it means that I do the pumps first, I am thorough with deep-breathing and then I do pumps at four different parts of the body. After that, I do shoves, in a certain order Participant #12

Self-care by methods such as an infrared sauna, vibration boards, and compression with tights designed for exercise were also described with mixed outcomes. Other methods tested by women included aquatic exercises or cognitive therapies, such as Qigong, deep breathing, meditation, and yoga. Dietary alterations were another frequently reported method to improve symptoms from lipedema. Women who had tried traditional low-calorie diets recounted negative experiences, noting that such diets neither alleviated their pain nor resulted in weight loss. Other diet regimens were an anti-inflammatory diet, LCHF (Low Carbohydrate, High Fat), ALP (Anna’s leptin protocol, described by the women as a stricter version of the anti-inflammatory diet), Cambridge diet (containing low-calorie meal replacements), ketogenic diet (high-fat, low-carbohydrate diet), gluten-free diet, and lactose-free diet, all with mixed results.

I have tried everything except liposuction, but during that time I ate an anti-inflammatory diet for 8 months, and these last four months I have used the APL-diet. It’s even stricter where you avoid all gluten, all sugar, dairy... Participant #3

Discussion

To our best knowledge, our study is the first to explore the experiences of women with medically verified lipedema seeking healthcare. Previous studies investigating the experiences of patients with lipedema,^{9,10} have described challenges in healthcare, consisting of deficient support from healthcare professionals, limited knowledge of lipedema among healthcare professionals, and unavailability of treatment. The impairing symptoms of lipedema had negative effects on the affected women's economy, making it more challenging to obtain the care they wanted. Most treatment options for lipedema were not subsidized by publicly financed care in Sweden; hence, women reported having had to pay for these costly treatments themselves. The women also described that treatment options could be a challenge to access, as few specialists recognized the signs and symptoms of lipedema and could suggest a treatment. The struggles of women to receive understanding and support for lipedema, together with the difficulties in accessing basic or, in some cases, advanced care, can be described by our theme "Pushing the barricaded doors to treatment and care while fighting to illuminate the shadows of lipedema".

Facing judgment and disbelief from healthcare professionals has previously been described in other conditions, such as obesity, as harmful to the interaction with healthcare.²¹ While women with lipedema have a different condition and have different symptoms, such as pain and a different distribution of the adipose tissue than people with obesity, the prejudice and stigma our participants described aligns with those described by people with obesity.

Additionally, a previous questionnaire study described that women with lipedema often have tried various treatments with dissatisfactory results.²² In this study, the results indicated a high variation in satisfaction with different therapies described for lipedema. Women who had tried conservative or surgical treatments, with unsatisfactory outcomes, resorted to complementary or alternative treatments for ameliorating their symptoms. While alternative treatments were reported to reduce symptoms to some extent, they are not recommended by healthcare nor described in available guidelines for lipedema.

Another remark is that persons included in previous studies,^{9,10} contrary to our participants, have a self-reported lipedema diagnosis, which might introduce biases associated with this methodology. Having physician-diagnosed informants enabled us to investigate the experiences of inequality in healthcare on an organizational level. The absence of lipedema in guidelines and political prioritizations was described by the women to cause experiences of ignorance, delayed diagnosis, and difficulties obtaining treatment. The right to health differs from the entitlement to being healthy. While the United Nations has suggested a standard of highest achievable health rather than absolute entitlement to being healthy, it has also provided some key elements, such as I. Accessibility, II. Availability, III. Acceptability, IV. Quality, V. Participation, VI. Accountability, VII. Freedoms, and VIII. Entitlements, ie critical components for living and sustaining a healthy life.²³ Considering the findings in our study, several aspects of these key elements may be improved, as there is no international or national consensus specifically dedicated to the care of women with lipedema. Therefore, it is important that the scientific community increases efforts to provide data regarding diagnostic methods and treatments for lipedema, as suggested by the Swedish Agency for Health Technology Assessment and Assessment of Social Services.^{12,24}

Since there is no cure for lipedema, healthcare must become more accessible and strive to support and address treatable problems described by affected women, such as pain, a feeling of heaviness, and movement disabilities. Failing to provide the necessary care may exacerbate the financial situation for women with lipedema, as the disease can cause additional medical conditions, such as obesity, lymphoedema, depression, and anxiety.^{25–27}

Women suffering from lipedema reported dissatisfaction with the unequal access to treatment, particularly when compared to other healthcare-managed conditions. Additionally, they experienced challenges such as geographical distance to care and the scarcity of clinics specializing in lipedema management, negatively impacting their quality of care. Effective resource management in healthcare, education, training of employees, and collaboration among providers could improve the quality of healthcare by providing better care for those affected.²⁸ It is thus important that the scientific community increases efforts to provide data regarding diagnostic methods and treatment for lipedema, as suggested by the Swedish Agency for Health Technology Assessment and Assessment of Social Services.^{12,24} Another finding was that women with lipedema described experiences of exclusion and being denied treatments by their healthcare providers. Allowing women with lipedema to influence their care and ensuring that they are met with respect and engagement

would strengthen their ability to manage their condition, which also aligns with the Swedish Patient Act.²⁹ This would further empower them to take control of their health and well-being instead of being passive victims of their condition.

Finally, our findings suggest that creating patient information for lipedema and making it available for healthcare professionals to use in their contact with lipedema patients could have significant clinical implications. Patient health information materials have previously been shown to be valued by patients and to improve the patient-physician interaction.³⁰ Future research should prioritize investigating the specific psychological and physical impairments in lipedema as it would advance our understanding of disease mechanisms, improve patient outcomes, and enhance the quality of care provided to individuals living with the condition.

Strengths and Limitations

A major strength of this study was that patients included were clinically diagnosed with lipedema, which reduced potential biases and enhanced cohort homogeneity. While this method limits the number of informants available for participation, it increases the overall trustworthiness of our findings. It is also important to consider that the informants received their diagnosis by JD in collaboration with AS and EN and were later interviewed by JD. Although JD was not involved in the informants' care beyond the diagnostic visit, we cannot dismiss the possibility that the interview context or the physician-patient dynamic influenced how informants shared their experiences.

Finally, although qualitative research may face limitations in generalizing findings to a broader population due to the significance of social and cultural contexts, the findings of this study offer valuable insights into women's experiences of lipedema. The results of this study provide an opportunity to enhance healthcare professionals' understanding and capacity to recognize and evaluate the challenges encountered by patients with lipedema when seeking healthcare.

Conclusion

Lipedema remains a mainly unknown disease with few available treatments in subsidized healthcare. The perceived lack of experience regarding lipedema among healthcare professionals and their failure to assess the condition risks damaging the confidence of affected women in the healthcare system. Therefore, increasing awareness and education among healthcare personnel to increase clinical recognition of lipedema is a necessary first step to reduce misdiagnosis, improve patient satisfaction, and the availability of care among of patients with lipedema.

Ethical Considerations

Ethical approval was obtained from the Swedish Ethical Review Authority, no. 2019-06344, and addendum no. 2021-01138. All informants received oral and written information about the study and gave oral and written consent to participate, including publication of anonymized direct quotes. Participants could withdraw their consent at any time with no consequences for their future care. Each interview recording, as well as the transcriptions, was coded to ensure anonymity. This study also adhered to the Helsinki Declaration and Standards for Reporting Qualitative Research (SRQR) ([Supplementary Material:2](#). Standard for Reporting Qualitative Research (SRQR)).³¹

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

The authors report no conflicts of interest in this work.

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