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Women’s experiences of living with lipedema

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ABSTRACT

Lipedema is a chronic, progressive disease that almost exclusively affects women and often misdiagnosed as obesity or primary lymphedema. Research concerning lipedema is sparse, and there is a lack of studies focusing on women’s experiences of living with the illness. We interviewed fourteen women with lipedema with the aim of describing their experiences of living with lipedema. Our results show that women felt controlled by their body, and were fat-shamed and viewed by others as a person who lacked character. They received unsupportive advice on how to manage from healthcare, and blamed themselves while striving to take responsibility.

Lipedema is a chronic, progressive disease with an unknown etiology that almost exclusively affects women. The disease is underdiagnosed and often misdiagnosed as obesity or primary lymphedema. In lipedema, abnormal depositions of subcutaneous fat cause bilateral swelling and enlargement of the buttocks and legs, which develop slowly and gradually. Lipedema is associated with discomfort, bruising, and severe pain in affected areas, as well as limited mobility. Typically, the disease starts during or soon after puberty, but it can also start in connection to pregnancy or menopause. Since the progression of lipedema varies to a great extent, it is difficult not only to predict the course of the disease but also to control it. There are no easy solutions to treat lipedema. Conservative therapy is often used, which focuses on patient education, weight control, manual lymphatic drainage therapy, and compression therapy. Surgery, such as liposuction, may also play a part in the management of the disease. Lipedema is associated with both physical and psychological morbidity, making it vital to provide adequate care and support (Buck & Herbst, 2016; Forner-Cordero et al., 2012; Langendoen et al., 2009). Lipedema concerns the women’s health and the disease has no known geographical boundaries. While the hidden statistics are probably large, epidemiological studies suggest an approximately 10–15%
prevalence in the female population worldwide (Buck & Herbst, 2016; Forner-Cordero et al., 2012).

For women who live with lipedema, daily life is affected in several ways, and there is evidence that the disease has a great impact on the one's quality of life (cf. Dudek et al., 2016; Romeijn et al., 2018). Okhovat and Alavi (2015) showed that there is extremely limited knowledge about lipedema, and there is a lack of studies that focus on women's experiences of living with the illness. Herbst (2012) showed that lipedema often is mistaken for lifestyle- or diet-induced obesity, rendering in stigmatization and a lack of effective treatment for the women affected (Buck & Herbst, 2016). Furthermore, this stigmatization affects the women's opportunities to be taken seriously in healthcare settings. Herbst (2012) also stressed that, with a lack of accurate treatment, women with lipedema are faced with social stigma rooted in the fact that other people tend to judge women based on a negative view of bodily appearance and health ideals. Throughout history, and even today, the female body can be understood as a constrained body, due to health and social ideals that imply negative attitudes toward variation in bodily appearance (cf. Connolly, 2001; Johannisson, 1994; Sherwin, 1992). The unclear treatment for lipedema, contradictory advice on the Internet, and uncontrolled bodily changes also affect how women who live with lipedema view their own bodies, and feelings of helplessness can occur in relation to being left without adequate support (Dudek et al., 2016). Lipedema with its manifestations affecting the quality of life call for further knowledge on the women's experiences related to the disease (cf. Okhovat & Alavi, 2015). It is well known that living with long-term illness affects the women's self-perception and self-esteem (Toombs, 1993).

In addition to the visible symmetrical, enlarged legs, lipedema is also related to pain and fatigue (Romeijn et al., 2018). Women with long-term illnesses have described pain and fatigue among the worst symptoms, which have a significant impact on their everyday lives. An important aspect of this is the fact that these are invisible symptoms, making them challenging for others to understand. For women who experience pain and fatigue, this lack of understanding means neglect and even a feeling of not being taken seriously or believed (cf. Dudek et al., 2016; Juuso et al., 2011; Olsson et al., 2008). The perceived lack of understanding also affects encounters with healthcare, and women have described these encounters as strongly driven by acting as “a credible patient” (Hansen et al., 2014; Werner & Malterud, 2003). Women with lipedema should be met with dignity and respect during healthcare encounters and that healthcare professionals should manage and strive to understand the woman in need of care. Therefore, knowledge of the women's experiences is important to acknowledge both visible and invisible symptoms and how these affect women's daily lives (cf. Hansen et al., 2014; Juuso et al., 2011; Olsson et al., 2008).
Aim

The aim of this study was to describe women’s experiences of living with lipedema.

Materials and methods

A qualitative approach was used to target the experiences of women with lipedema. Women’s experiences were derived from individual qualitative research interviews with a narrative approach to promote a systematic and consistent data collection method. Data were analyzed using a qualitative content analysis method in accordance with Graneheim and Lundman (2004).

Participants and procedure

Fifteen women with lipedema were recruited to participate in the study. One participant was excluded since she could not be reached. In total, fourteen women participated in the study. The participants were located throughout Sweden, representing a geographical spread. The inclusion criteria for participation were that they had a confirmed diagnosis of lipedema by a physician, and that they were willing to share their experiences. Their ages ranged from 30 to 60 (m = 46.4 years), and they were diagnosed with lipedema 1–15 years (m = 4.3 years) ago. All women had experienced symptoms for several years prior to receiving the diagnosis. Thirteen women lived with a partner, and one lived alone. Eight were on full sick leave, one received state pension, and five worked full-time or part-time.

The women were purposely recruited through postings in lipedema interest groups on social media. We contacted a previously known key person to ask if she could post an information text about the study in lipedema interest groups. The key person posted the text in several groups on social media. If women were interested in participating, they contacted us via email or phone. We sent information letters to the women to provide further information and obtain informed consent. The information letter included a reply form and after they had agreed to further contact, we called the women to arrange an interview.

Data collection

Individual audio-taped interviews were conducted during 2019 using a qualitative and narrative interview approach (cf. Kvale & Brinkmann, 2009). Two of the authors performed the data collection, and interviewed half of the group each. The interviews were performed by phone, which provided an opportunity to recruit women with a geographical spread.
We strived to take on a stance of immediacy and presence when interviewing, with an effort to create a relaxed and intimate atmosphere where the participants could talk freely. An interview guide was used to explore the experiences and challenges that may affect the participants' daily lives. Probing and clarifying questions, such as “What is it like for you?” “How did you feel?” “Can you please tell me more?” and “Could you give an example?” were asked to gain a rich description of the women's experiences. The interviews lasted between 40 and 60 min and were transcribed verbatim.

**Data analysis**

To analyze the transcribed interviews, we undertook a qualitative content analysis in accordance with Graneheim and Lundman (2004). Transcripts were read through several times to gain a sense of content and data as a whole. Meaning units were then extracted and condensed, without losing their core. The next step was to search for patterns and relationships among the meaning units. In this process, meaning units that shared the same central meaning were grouped together stepwise to form categories. Throughout this process, we conducted continuous discussions to verify the emerging categories. The analysis process ended when no further abstraction was deemed appropriate. We then translated categories and quotes into English.

**Ethical considerations**

This study was approved by the Regional Ethical Board (Dnr. 2017/471-31). All participants were given verbal and written information about the nature of the study, which included information about ethical rules and principles that had been taken into account, such as informed consent, confidentiality, right to not be harmed or identified, and the ability to withdraw at any time (Polit & Beck, 2016). All participants gave their verbal and written consent to participate. All personal data related to participants were protected with established and accepted principles for data security, including the data being de-identified, confidentially processed, and protected in a manner in which only authorized people in the research team had access to the information. Written data were handled in the same manner and kept locked up.

Being interviewed can be both open and intimate, leading to participants narrating more than intended or coming into areas they would rather not discuss (cf. Oliver, 2010). It was important that the participants were not overly exposed by revealing their thoughts and opinions. Therefore, we were vigilant to the participants’ narrations by letting them narrate at their
own pace and take time to choose what they wanted to talk about, approaching sensitive areas carefully. Having the opportunity to talk about one's own experience can be a positive experience for the person being interviewed while simultaneously allowing participants to be involved in increasing the knowledge within the subject under study (cf. Oliver, 2010).

Results

Being controlled by an unreliable and burdensome body

Women with lipedema described their bodies as burdensome in their daily lives. When moving around, every single step was a gigantic effort. They felt hindered by their bodies and their heavy, swollen, and painful legs. Women described their bodies as unreliable, feeling controlled by them. Their bodies directed their everyday lives, and a sorrow was expressed over how the unpredictable body felt more and more unfamiliar. Women described an unbearable pain and expressed a feeling of the edema pressuring other organs. The pain was related to a heavy internal pressure on both nerves and blood vessels, and their bodies felt like exploding from within. Daily life was filled with an aching pain that could unpredictably worsen and become a stabbing sensation. The constant pain made them exhausted, and recurring nightmares about being tortured were described. Treatment with compression and being in water was said to give some support to the exhausted body, but it made no difference to the lipedema. Women with lipedema said that their condition was so severe that they could barely manage to participate in treatment. They expressed a constant uncertainty concerning the future. They feared what would happen if the lipedema got worse, or if they would be in need of support in their everyday lives.

It is painful, every step I take is so painful. When I sit down it is painful, it is so hard. I have a new kind of pain now. Before it was more of a pressure pain, and I would try to place my legs high, but this is something new. It is stinging in my skin. It is very scary, just as if someone were stinging you. It affects my general condition. I have to lay and rest all the time. I am totally exhausted. I feel so sad not having any energy. I meet no one.

As a consequence of avoiding additional pain, the women felt on guard and tried to shield themselves from being hugged or touched by others. They said that they lacked lust and felt unattractive, which impacted their capability to be sexually active, even though they might long for it. Believing that their spouses found them to be attractive and feeling closeness to their partners were expressed as essential. Nevertheless, the women felt that their spouses did not find them to be attractive. The changes in
their bodies made the skin feel limp and bumpy. The women felt that it was challenging at times to keep the body dry and clean, which contributed to smells, infections, and rashes in the folds in the skin.

I wish I could get really aroused, but, at the same time, I would not have the energy for it. Yes, it affects my life tremendously—my whole life, our life of course, not feeling desired by the man you are in love with. I tried to ask him: ‘It feels like you don’t think I’m attractive in any way.’ He is so kind and would never say it directly to me, instead, he asked me, ‘What do you want me to say?’ Then I realized that, no, he is not attracted to me, but he is in love with me. It was awful, but, at the same time, it became clear then.

**Lacking professional care by receiving unsupportive advice on how to manage**

Women with lipedema explained that they sought contact with healthcare professionals when they experienced changes in the body and increased pain. They were certain of something being wrong but felt uncertain and insecure concerning what was happening with their bodies. Prior to receiving the diagnosis, they had several encounters with doctors at primary healthcare centers and hospitals. They went through multiple exams for different illnesses, but as these did not show anything, not even the doctors knew what was wrong. Hence, women received advice to do weight loss exercises and received prescriptions to visit physiotherapists and dietitians. The women felt as if they were guinea pigs for healthcare.

Then I came in to see them [health care center], and they thought it was a heart attack. They told me that I was too fat and should not smoke. I’ve never smoked in my life and I seldom drink any alcohol because I used to be married to an alcoholic.

Women described advice from healthcare professionals as unhelpful on how to manage, making them struggle to gather information themselves. They sought knowledge about what was best for their well-being, tried out different diets, and searched for information to increase their understanding. For some women, this was how they found out about the diagnosis. They tried to explain what they had found to their doctors but were often met with skepticism and hurtful comments and glances. One woman said:

I found a picture of a woman who looked precisely like me, and she had lipedema. I decided to show the picture to my doctor. He, however, believed that this was just a way to put the blame on someone else. He said to me, ‘What are you doing here? Whose fault is it that you are fat? Is it your mother’s, your children, or someone else? By the way, you have curves in the right place.’ I felt so humiliated and did not understand why he reacted like that.
After years of searching for help from healthcare, the women explained that contact with a specialist or a lymph therapist led to their diagnosis. Initially after the diagnosis, the women described feelings of relief and confirmation that their feelings had been validated, that something was indeed wrong. The diagnosis was, however, not helpful as the doctors and other healthcare professionals lacked knowledge about lipedema and its management. When receiving the diagnosis, the women described that they felt alone, not knowing if anybody else had the illness or who to turn to for help. Receiving the diagnosis was described as a dead end, as they now knew what was wrong but did not receive any care despite the diagnosis. Instead, they had to fight to receive care. They felt overlooked and believed they needed to handle the illness by themselves, which led to a struggle with both self-care and seeking information. Women also described that they felt alone in their medical decision making, such as decisions about undergoing surgery, and were left to receive guidance from companies that made money on their situation.

I was so happy to get the diagnosis on paper, because I thought that, wow, now I have a diagnosis after all I have gone through. Now, no one can blame me for being overweight, saying that I am unfit, the diet, or something like that. However, I felt as though I had won a prize, but this prize was not worth anything as I haven't received any help afterwards.

When women with lipedema received treatment and medication, they described it to be based on the doctors' premises. For example, some of the women were prescribed diuretics, even though they tried to explain that these medications did not have an effect on lipedema. Furthermore, healthcare professionals were described as lacking knowledge about pain-relieving medicine and hesitated to prescribe it in case of drug dependence. The women felt that the healthcare professionals questioned their descriptions of the pain, touched them carelessly during exams, and did not listen to the women's descriptions of their experiences. Being questioned was described as offensive and led to feelings of violation of dignity. They described feelings of anger and misery, as the healthcare professionals did not apologize for their disrespectful treatment.

In contrast, some of the women had met doctors who listened to them and were open about their lack of knowledge about lipedema. With them, the women could discuss and plan for a proper treatment. They also had the possibility to educate the doctor, which was described as encouraging for their self-esteem. These doctors often referred them to specialists in order to obtain the right kind of care and treatment.

I have been lucky to have the doctor I have. He has really been wonderful and has a holistic view on me. He has been willing to help me. As there is a lack of
knowledge and guidelines about how to treat lipedema, I have read and passed on information to him, which he has been open to and got help from to understand my illness.

Women described that they had received various kinds of treatments, such as compression garments and lymph massage. The effects varied, and they often had to pay for the costs themselves. Some women had been offered gastric bypass surgery, which they felt was terrible as it was perceived as an expensive, risky procedure that would not help their lipedema. Women who had undergone gastric bypass surgery explained that the surgery worsened their feeling of being ill and made it even more difficult to manage. Meetings with psychologists were described as good for their overall health and self-esteem but did not help with their lipedema. Some of the women had been offered liposuction surgery for lipedema, while others stated that they had to fight for it. Furthermore, others had been in contact with clinics abroad to book a liposuction surgery and pay for it out of pocket. The effect of the surgery was described as amazing, as it eliminated the lipedema pain for the women; although they had pain in the remaining lipedema places on the body, they felt joy and viability.

**Being fat-shamed and viewed by others as a person who lacks character**

Women described how they felt judged by other people as lazy and lacking in character, and being fat-shamed was common. One woman who was pregnant described her midwife fat-shaming her, saying that she should take control of her eating for the baby’s sake. Women expressed how they felt others’ disgust, with the experience of being stared at and people turning their heads away. They tried to cover up their bodies from others’ external gaze. Even healthcare professionals were experienced as judgmental; for example, women who had gone through liposuction surgery stated that they were treated as though they had gone through a cosmetic surgery and had chosen this surgery to simply look better.

It is this shame. I don’t really know what people think, but I do not look normal. The worst thing is that people believe that I sit at home and just eat like a maniac, and that I’m a lazy person that doesn’t do anything. I carry that shame. It is the worst to be of less value. You want to hide. You do not want to show yourself.

The illness was described as both visible to others through parts of the body being disproportional and as invisible, since other people did not know that the disproportional body was due to an illness. The women wanted to tell others that their body shape was caused by an illness, and that it was not their fault. They felt disbelieved by other people when trying to explain their situation, and that they did not have a choice in gaining the weight from lipedema. They also felt disbelieved concerning
the amount of food they ate and the amount of exercise they performed, as if they had eaten more and exercised less than they said due to their increased weight. Not being believed was described as awful and heart-breaking. They felt judged by others who thought that they could just exercise and eat less, and that they had a choice in gaining weight.

I would like to tattoo into my forehead that I have a disease and that I am not lazy and incapable. Yes, I feel less worthy. Of course, that’s how it is.

Comments were made both behind the women’s backs, with people thinking that the women did not hear them, and directly to the women themselves. The women believed that other people felt entitled to comment on their body parts, saying statements such as, “My God, what big legs she has,” and “Those legs do not fit your body.” These comments were hurtful and reinforced the feeling of not being viewed as a person but rather as someone with less worth, the “fat one” or “the one with the big legs.” Even family and friends who had not seen the women in a while would comment on the changes in the women’s bodies, such as “What happened to you? You looked so nice last year.” Out in public, the women believed that people were thinking about their changed bodies and talking behind their backs, leading to shame about their bodies and a fear of being judged when going out.

I remember it so well. In physical education, after class ended one day, a classmate told me, “You have such a narrow waist. You even have a narrower waist than I do. How come your legs are so big?”

**Blaming oneself and feeling guilty while striving to take responsibility**

When women with lipedema felt they did not manage to handle the illness, they blamed themselves, thinking that it was their own fault since they were the only ones responsible for handling the illness and its consequences. The women said that they lived with a sense of guilt stemming from thoughts of the pain being a result of them doing something wrong. They described the guilt from being a burden to close relatives and friends. For example, one woman stated that her husband pulled a heavy load in their everyday lives, and she did not want to burden him anymore. The women felt guilt about not being able to take care of their children and provide economically for the family. It could be challenging for spouses and children to really understand their situation with pain, fatigue, and strain. For example, the women’s children did not understand why they could not cuddle or sit in their mothers’ laps, which was described as heart-breaking. A sense of guilt was often related to eating, especially when eating something unhealthy even if it was on rare occasions. Eating
too little, however, also led to feelings of guilt as they knew that starvation was not beneficial. The same was described when it came to exercising, where a sense of guilt and blame set in if they did not exercise, even though they were exhausted. Women with lipedema described a strong willpower to get better and took great responsibility and ownership to find ways to manage their illness and receive care and treatment. They felt each day was a struggle, and they fought to manage everyday tasks.

Because I was so sick, I felt that I was completely exhausted. I think that many people with lipedema fight hard. No one knows and you are expected to manage, even if you feel that something in your body is not working and you can't explain why. You fight so hard for so long, so you finally break down, and I did. But then I decided to fight to get to a functional level of health, because I wanted to […]

Women with lipedema strived for a balance in what they wanted to do and what they were able to do related to pain and energy levels. The fear of pain and fatigue limited social and physical contact, and they felt alone. In their strive to handle their illness, the women found support and confirmation in others with similar experiences with the illness. Patient associations and interest groups created a sense of fellowship and communion where the women could feel understood and believed, without having to explain. They felt less alone and were strengthened in their fight to receive care and create a change for other women with lipedema. Interest groups on social media made it possible to discuss and receive information, as well as others’ experiences and opinions. However, these groups could also be misleading or promote a unilateral view in different areas. Sharing one’s experiences gave power and a feeling of helping others with lipedema.

Then I found groups on Facebook for lipedema. We also started a group here locally and have patient associations and such. The affiliation with others affected is very important, I think. When we meet, we understand each other exactly. We don’t have to say much, and, at the same time, most of us are very sensitive, so we can support each other in this difficult situation. It feels extremely important

**Discussion**

Having done this study, we have learned that women with lipedema live with an illness that severely restrains their everyday lives. The women felt controlled by an unreliable and burdensome body. We also learned that they lacked professional care by receiving unsupportive advice on how to manage. In social settings, as well as in healthcare encounters, women with lipedema were fat-shamed and viewed by others as a person who lacks character. The women blamed themselves and felt guilty while striving to take responsibility, and they felt alone and left behind without any help
to manage daily living. The evident lack of care and medical treatment, can from a feminist ethics point of view be understood as threatening the rights to equal care for women living with lipedema. A striking issue that we aim to highlight regarding the results of this study are the fact that women with lipedema are treated unjustly in healthcare encounters. Therefore, we discuss the study results using literature that allows a problematization of issues concerning gender equality and power. We pay attention to both individual and structural issues concerning the health of women with lipedema. The first person perspective serves as a starting point, and we also use literature problematizing the terms of women when seeking healthcare from a feminist approach to discuss the results.

This study shows that the consequences of the disease, with enlarged and painful body parts, affected every aspect in the everyday lives of women with lipedema. When moving around, every singular step was described by the women as a gigantic effort. Carel (2008) describes the body as central to people's experiences of being ill. Unlike the healthy, unnoticed body, the experience of illness changes the perception of one's own body. Due to bodily failure or change, the body becomes noticeable and evident in daily life, rendering in the body serving as a hindrance. For women with lipedema, their bodies felt unreliable, and they lacked control over the unpredictable body that became more and more unfamiliar. Toombs (1993) described that the ill body implies loss of control in everyday life. The ill body changes from previously being useful to becoming a threat to a person's very existence. In order to deliver a care corresponding to the needs and expectations of women with lipedema, we believe that the first person perspective on living with a painful and unpredictable body needs to be considered.

The results in this study showed that women with lipedema felt ashamed and that they were judged by other people as lazy and lacking in character; being fat shamed was also a common experience. They expressed how they felt others' disgust and the experience of being stared at and others turning their heads away. This can be understood as the women feeling stigmatized in their daily lives. Kleinman (1988) referring to Goffman (1963) explained the link between stigma and feelings of shame among people who are ill, specifically how visible stigma in relation to the marked body is deeply discrediting with regard to others' external views. The stigmatized person is often viewed by others as an alien other whose attributes are in opposition to the valued attributes of a group. Due to having visible non-valued attributes, such as enlarged body parts, all relationships for this person are affected. The shame that the person experiences can be viewed as a response to the reactions of other people. In this study, women with lipedema tried to cover up their
bodies from others’ external gaze. They viewed themselves as ugly and abnormal, and felt ashamed. Kleinman (1988) described that there is an expectation from others that an ill person should cover or normalize his or her status or condition. One’s sense of shame arouses due to the others’ inattention but also by others’ embarrassing expressions. We suggest that the feelings of shame in women living with lipedema can be viewed as related to being visibly marked by the ill body and the others’ responses to their appearance. Related to this Leder (1990) described how the external gaze of others increases the feeling of being objectified as an outsider among people who are ill. This is further reinforced by the dictating norms of contemporary culture that state that women should be attractive and have a certain form. Sherwin (1992) explained that women’s worth is often judged by the shape of their bodies. Being considered by society as fat, which were common among women with lipedema, is, according to Sherwin (1992), defined as a social failure as a woman. In addition, Sherwin stressed that healthcare needs to take a further holistic approach on women’s health and offer care and medical treatment when indicated and needed in the same manner that men are offered. Women who are viewed or considered to be fat, unlikely from other conditions or diseases, are strongly directed by authorities to take responsibility for their bodies and learn self-control in their eating patterns. This can be related to Connolly (2001) who explained how the normative ideal of health and bodily appearance causes exclusion, and how women’s conditions often are devalued in healthcare and medicine. In this study, women with lipedema were often blamed and advised to manage and control their situation, which we believe can be viewed as a feminization of disease serving to silence women in healthcare encounters, and leading to lack of competent and professional care and medical treatment.

In this study, women with lipedema fought to receive care and treatment to support their exhausted bodies, but they were often left with treatments that made no difference to the lipedema or the pain. They lacked professional care that could support them to manage the illness. Instead, they received unhelpful advice and experienced the healthcare professionals lacking knowledge about the illness and treating the women with skepticism. They struggled to find explanations for their experiences of the changed body and pain. Bury (1982) stated that when persons with chronic illness face others’ lack of knowledge about their illness, their own search for explanations and strategies to cope with daily life starts, which can be both long and difficult. Inconsistent conditions are, according to Connolly (2001), ignored and minimized by healthcare professionals, as they are not accepted as accurate and truthful in the medical encounter.
This kind of rejection of the chronically ill person is more common among women. Uncommon or unfamiliar conditions, such as lipedema, tend to be feminized, thus raising questions about the patients’ credibility (cf. Connolly, 2001). In this study, the experience of not being considered to be trustworthy was striking and implied a great suffering among women with lipedema. Our suggestion is that women with lipedema are wrongly judged due to a lack of knowledge about their disease as well as societal values on how women ought to appear. It has been stated that women seeking care should try to adapt to perceived expectations within the healthcare context. For women with long-term illnesses, efforts are often required to make symptoms socially visible and physically expressed when healthcare professionals are consulted. It can be described as a clear struggle for credibility and an attempt to balance between not acting too weak or too strong, too smart, or too unfocused (Herbst, 2012; Werner & Malterud, 2003). Malterud (1999) stressed that the social view on the female body often tends to affect healthcare encounters. According to Connolly (2001), different behaviors are expected from women and from men and in clinical practice; the same behavior is often understood very differently depending on the patient’s gender. This gendered view has an impact on how women who seek care are treated and met. A healthcare encounter demands great effort from the ill person, and not being understood, believed or given time creates a feeling of being robbed. Healthcare professionals need to understand the relation between stigma and shame and how it affects a person in a specific situation. Hence, it becomes important to legitimize and authorize the person’s illness experience (Kleinman, 1988). Toombs (1993) expressed the need to approach an understanding of the ill person’s experience from an insider view. To gain an insider view, it becomes important to link stigma and shame but also the loss of bodily integrity and certainty in daily living.

The results in this study showed that women with lipedema lived with an unbearable pain. As the severe pain was invisible to others, women with lipedema felt a lack of understanding from other people as well as from healthcare professionals. For pain to be made visible, it needs to be given a voice, not only by the person in pain but also by those who might be able to relieve it. In clinical practice, however, there are many ways of keeping pain private and invisible, thus denying or casting doubt on its facticity (Madjar, 1999). Thus, making pain visible is a joint project that requires the patient’s body and voice to be believed, rather than doubted or bypassed (Scarry, 1985). The first step in the alleviation of pain is not to doubt its reality but to acknowledge its presence. To doubt the reality of patients’ pain or to dismiss it as something merely unpleasant or uncomfortable “amplifies the suffering of those already in pain” (Scarry, 1985, p.
It also creates distance between the patient and the healthcare professionals, making the understanding of the patient’s experience of pain more difficult and the alleviation of pain less likely. In healthcare encounters, patients usually try to be cooperative and to retain composure by restraining their body and voice (Madjar, 1999). The already private pain experience is made even less visible to others. It is when the healthcare professionals believe that this controlled outward expression is the whole of the patient’s experience that pain becomes even more hidden and therefore, easier for the healthcare professionals to ignore and overlook (Lawler, 1999). For women with lipedema, we suggest that it is important that healthcare professionals take on an attentive approach when attempting to understand their pain and suffering and to create a comprehensive picture of their situation. A crucial starting point to formulate actions and treatment plans is to see the other person and recognize and understand her needs. Frank (2004) emphasized the vital value that recognition of pain and suffering has on the person living with it. Recognition creates a power that makes it bearable for the person living with pain and suffering.

In this study, it is obvious that women with lipedema meet healthcare professionals who know too little or nothing at all about the nature of their condition. Women are shamed by others including poorly trained healthcare professional, but alleviated by those who have knowledge of women’s correct diagnosis. Still to date, women with bodies that do not follow the societal norm may be exposed to healthcare professionals that tend to blame the women for their condition, rather than recognize them as victims of a disease (cf. Sherwin, 1992). Women are often blamed for their weight, and stigma toward women with large bodies may have an impact on their physical and psychological health (cf. Puhl & Heuer, 2010). This stigmatization leaves women with lipedema alone without adequate support on how to manage. Stigmatization of women with lipedema focusing merely on their weight and large body may threaten their health, can lead to health disparities, and leave the women without a correct diagnose and adequate care. The findings in this study highlight the vital aspect of shifting the focus from women’s personal responsibility of their body size to an issue of social justice and the right to equal healthcare.

**Conclusion**

Women with lipedema live with an illness that severely restrains their everyday lives. On the one hand, they have visible attributes, such as enlarged legs, as consequences of the disease. On the other hand, the disease is still invisible since it is not evident to other people that these enlarged legs are a result from a disease. This renders both stigma and shame in daily life. The feelings of shame in women living with lipedema
can be described as related to being visibly marked by the ill body and others’ responses to their appearance. The women are often blamed and advised to manage and control their own situation, which may silence them in healthcare encounters. The findings in this study highlight the vital aspect of shifting the focus from the women's personal responsibility of their body size to an issue of social justice and the right to equal healthcare. Women with lipedema live with an unbearable pain, and for this to be made visible, it needs to be given a voice, not only by the person in pain but also by those who might be able to relieve it. Making pain visible is a joint project that requires the patient’s body and voice to be believed, rather than doubted or bypassed. Doubting the reality of the patients’ pain amplifies the suffering of those already in pain. By disbelieving women with lipedema, the already-private experience is made even less visible to others. Having one's pain and suffering recognized and confirmed is vital, since this creates a power that makes it bearable.

Disclosure statement
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