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ORIGINAL RESEARCH

Comprehensive Needs Assessment for Enhancing Self-Management in People with Lipoedema and the Support Provided by Their Healthcare Professionals

Lise Maren Kloosterman[1–4], Harriët Jager-Wittenaar[1,2,4,5], Francine Schneider[6], Ad Hendrickx[1,3], Rienk Dekker[7], Aldo Scafoglieri[4,8]

[1]Research Group Healthy Ageing, Allied Health Care and Nursing, Hanze University of Applied Sciences, Groningen, 9714 CA, the Netherlands; [2]FAITH Research, Groningen, 9714 CA, the Netherlands; [3]Center of Expertise for Lymphovascular Medicine, Nij Smellinghe Hospital, Drachten, 9202 NN, the Netherlands; [4]Experimental Anatomy Research Group, Department of Physiotherapy, Human Physiology and Anatomy, Faculty of Physical Education and Physiotherapy, Vrije Universiteit Brussel, Jette, Brussels, 1090, Belgium; [5]Department of Gastroenterology and Hepatology, Dietetics, Radboud university medical center, Nijmegen, 6500 HB the Netherlands; [6]Department of Health Promotion, Care and Public Health Research Institute CAPHRI, Maastricht University, Maastricht, 6200 MD, the Netherlands; [7]Department of Rehabilitation Medicine, University of Groningen, University Medical Center Groningen, Groningen, 9700 RB, the Netherlands; [8]Frailty in Aging Research Group, Faculty of Medicine and Pharmacy, Vrije Universiteit Brussel, Jette, Brussels, 1090, Belgium

Correspondence: Lise Maren Kloosterman, Research Group Healthy Ageing, Allied Health Care and Nursing, Hanze University of Applied Sciences, Petrus Driessenstraat 3, Groningen, 9714 CA, the Netherlands, Email l.m.kloosterman@pl.hanze.nl

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Background: The cause of lipoedema remains unclear, and the condition is currently incurable. Effective self-management is therefore essential for coping with its physical and psychological impacts and the necessary lifestyle adjustments. This study aimed to assess the needs, barriers, and facilitators for enhancing self-management and self-management support from the perspectives of people with lipoedema and the healthcare professionals (HCPs) involved in their care.

Methods: The study used a mixed-methods approach, incorporating a narrative review focused on people with chronic conditions and their HCPs, along with focus groups involving people diagnosed with lipoedema and the HCPs involved in their care. The Core Processes of the Intervention Mapping method guided a systematic approach to address the study's objectives. Qualitative data were analyzed using a grounded theory approach.

Results: Findings revealed unique self-management barriers for people with lipoedema, including limited awareness and expertise among HCPs, as well as stigmatization from both HCPs and society. Participants identified a need for tailored lifestyle plans, guidance, and support for monitoring progress. Key facilitators included self-management skills, supportive networks, and role models. HCPs noted barriers in communication and collaboration due to a lack of specialized professionals and negative attitudes toward lipoedema. They expressed a need for multidisciplinary/interprofessional teams, accurate diagnosis, patient openness, and reliable information resources. Facilitators included fostering trust, encouraging patient participation, and setting achievable goals.

Conclusion: This study underscores the need for tailored self-management interventions for people with lipoedema. The adaptation of existing self-management strategies from other chronic conditions should take into account the specific needs, barriers, and facilitators of people with lipoedema and their HCPs.

Keywords: lipoedema, self-management, needs, barriers, facilitators

Introduction

Lipoedema is a chronic condition characterized by a painful and disproportionate accumulation of adipose tissue in the legs and, in some cases, the arms.[1] Living with lipoedema can negatively impact people's functioning and quality of life due to pain, as well as fatigue, reduced physical capacity, and physical limitations associated with the increased size of

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the legs and arms.[2–5] In addition to physical challenges, individuals may experience psychological issues such as anxiety and eating disorders, as well as the negative effects of self-stigma or feeling stigmatized.[6,7]

The cause of lipoedema remains unclear and the condition cannot be cured. Therefore, people with lipoedema must learn to manage its consequences.[3,8,9] Effective self-management is crucial for coping with the physical and psychological consequences, as well as for making necessary lifestyle adjustments.[10] This aligns with the current trend in healthcare, which is shifting toward a chronic care model that emphasizes long-term solutions to address the increasing burden of chronic conditions on healthcare systems.[11] Crucial to this shift is the emphasis on self-management as a central aspect.

Self-management involves actively monitoring one's condition and making the cognitive, behavioral, and emotional adjustments necessary to maintain a good quality of life.[10] Effective self-management not only helps individuals navigate the daily challenges of living with a chronic condition but also fosters a sense of control over their health, which is crucial for perceived quality of life.[12–14] Additionally, strong self-management skills enable individuals to adapt flexibly to evolving healthcare needs.[15] With the growing demand for self-management in chronic patients, the need for self-management support is increasing. Self-management support involves providing education and interventions that empower patients to manage the impact of their condition, helping them develop the skills and confidence needed to sustain healthy behaviors over the long term.[14] For self-management to be effective, a patient-centered, collaborative approach with healthcare professionals (HCPs) is essential, requiring patients to take an active role while ensuring their needs and preferences are integrated into a tailored treatment plan.[16–18]

Several studies have explored the perspectives of both patients and HCPs regarding self-management and support across various chronic conditions. These studies have shown that effective self-management and support are influenced by multiple factors related to both patients and HCPs.[12,13,19,20] Although there are similarities in these perspectives across different chronic conditions, each patient population and condition is unique. For people with lipoedema, a complicating factor in self-management could be that physical issues represent only part of the problem. Many also experience stigma and shame, which can contribute to participation challenges and reduced functioning.[6] Currently, no interventions for improving self-management specifically address the unique needs and preferences of people with lipoedema or are tailored to the distinct characteristics of their condition.

Therefore, the aim of this study is to conduct a comprehensive needs assessment for self-management enhancement by gathering information on the needs, barriers, and facilitators for self-management and self-management support from people with lipoedema and the HCPs involved in their care. This approach aims to gain a holistic understanding of self-management and address gaps in prior research. The needs assessment can inform the development of a self-management intervention by identifying key behavioral, environmental, and personal factors that contribute to the challenges faced by people with lipoedema and mapping the causal pathways that influence their ability to self-manage the condition and maintain quality of life.

Methods

Study Design

A mixed-methods study approach was employed to conduct a comprehensive needs assessment on self-management and self-management support in people with lipoedema and the HCPs involved in their care (Figure 1). This study adopted a comprehensive approach by integrating the perspectives of people with lipoedema and HCPs. These findings were triangulated with insights from other chronic conditions to provide a holistic understanding of self-management needs, barriers, and facilitators. The steps of the Core Processes, as outlined in the Intervention Mapping method, were used as a systematic framework to guide the study objectives.[21] This method integrated problem definition and solution development by combining expert knowledge, empirical data, theoretical insights, and additional research to ensure that existing knowledge is effectively applied and new research is both relevant and insightful.[22] The study was reported in accordance with the Mixed-Methods Reporting in Rehabilitation & Health Sciences (MMR-RHS) checklist.[23]

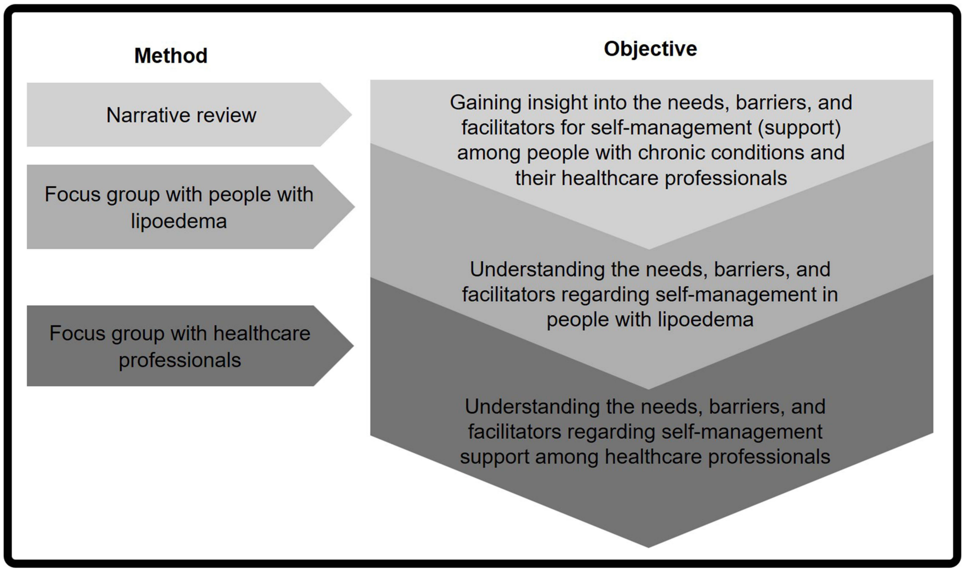

Figure 1 Flowchart of study methods.

Data Collection

First, a narrative review of qualitative studies was conducted to gain insight into the needs and preferences for self-management and self-management support among people with chronic conditions and HCPs. Conducting this review before to the focus groups established a strong foundation for contextualizing findings, developing questions, and enhancing the validity of the results. A thematic synthesis of qualitative studies from 2015 was used as the basis for the narrative review, as the authors identified the needs related to self-management and self-management support in people with chronic conditions.[12] To ensure that no relevant new information on this topic was overlooked, an updated search was conducted, including articles from 2013 onwards. The search string was based on the original strategy used in the thematic synthesis. Searches were carried out in PubMed, CINAHL, and Cochrane using tailored search strings (Appendix I). The keywords used were "self-management", "chronic disease", and "qualitative research", along with their synonyms. The databases were searched for eligible publications on July 4, 2024. Articles had to meet all of the following criteria: focus on self-management, involve adults with chronic conditions, explore support needs from the perspectives of people with chronic conditions or HCPs, use qualitative methods, be published from 2013 onward, and be written in English. We included adults with chronic conditions as studies on self-management in people with lipoedema or in HCPs taking care of people with lipoedema are lacking. Review articles were preferred, due to their high level of evidence. Potentially relevant publications from all sources were exported to EndNote.[24] After de-duplication, one researcher (LMK) screened the publications for eligibility based on titles and abstracts. The screening process continued with full-text screening, performed by the same researcher.

The narrative review provided input for the focus groups with people with lipoedema and HCPs. The focus groups were conducted in September and October 2024. The extracted themes regarding the needs, barriers, and facilitators concerning self-management and self-management support, as perceived by both people with chronic conditions and HCPs, formed the basis for the interview guides (Appendix II and III). The focus groups were led by LMK, a physical therapist and clinical health scientist trained in conducting interviews, along with an assistant moderator (MO). The primary reason for choosing focus groups over individual interviews was to foster interaction among participants, as varied responses stimulate discussion, facilitate idea development, and lead to solutions to issues.[25] To yield rich data, semi-structured interviews were conducted, combining pre-planned questions with emergent questions depending on the dialogue between the interviewer and the participants.[26] Considering that participants of the focus group resided throughout the country and to ensure broader geographical representation, the focus groups were conducted online.[27] Participant interaction was fostered by encouraging experience-sharing through specific questions, guiding discussions, and providing positive affirmation to create a safe atmosphere. All focus group interviews lasted one and a half hours. With each participant's consent, the focus groups were audio recorded.

Recruitment and Eligibility Criteria

Convenience samples of Dutch people with lipoedema and HCPs were asked to participate in this study. As an integral part of standard care at the Center of Expertise for Lymphovascular Medicine (ECL) at Nij Smellinghe Hospital, each individual visiting is routinely asked by a nurse to sign a general informed consent form during intake. This consent form inquires whether individuals are open to participating in research in general and whether they are willing to be contacted by a researcher in such cases. Individuals who signed the consent form were contacted consecutively to inquire whether they would like to participate in the focus group. The target population for the focus group with people with lipoedema consisted of people diagnosed with lipoedema by one of the dermatologists from the ECL. The reason for this specific inclusion criterion was the fact that due to the lack of consistent diagnostic criteria, lipoedema is often misdiagnosed or confused with other conditions.[28] Therefore, people were excluded when being self-diagnosed or diagnosed by another (medical) specialist. HCPs involved in treating and diagnosing people with lipoedema at the ECL or within the researcher's network received email invitations to participate in the focus group. Furthermore, for both groups, only people whose native language was Dutch and who were willing to share their experiences were included. People who were incapable of communicating, reading, or writing were excluded. All participants were contacted and invited by LMK and signed an informed consent form related to the study before the focus group meetings began. All participants provided their consent for the publication of anonymized quotes.

Data Analysis

Narrative Review

From the included studies, the relevant information about the population, the needs, preferences, barriers and facilitating factors of people with a chronic condition and HCPs regarding self-management and self-management support was extracted. Only information potentially relevant to the lipoedema population was extracted. Needs related to biomedical self-management for people with diabetes were considered irrelevant. For example, in the study by Nuno de Guzman Quispe et al, "fear of complications" was not extracted because it was specifically about blood glucose levels and insulin treatment. Additionally, "fear of dying prematurely during acute events" was not extracted, as acute events like exacerbations in COPD or chest pain in people with heart failure are not considered relevant problems for the lipoedema population.[13] Factors considered irrelevant by the primary researcher (LMK) were discussed with an independent researcher and physician (EP) to ensure no relevant factors were wrongly excluded from the review. The data extracted from the included studies were subsequently categorized into themes of needs, barriers, and facilitators concerning self-management and self-management support, as perceived by both people with a chronic condition and HCPs. In some cases, specific needs, barriers, and facilitators were given broader terms to encompass multiple related factors from the individual reviews, in order to create a more comprehensive overview.

Focus Group Meetings

The audio data from both focus groups were transcribed verbatim using Microsoft Word. The data were then analyzed using ATLAS.ti[29] by two researchers independently (LMK and MO). A grounded theory analysis strategy was employed to analyze the data.[30] The analysis comprised of three stages. In the first stage, the data were divided into small units, and initial codes were assigned (eg, initial code: "support in taking steps within one's own context"). While reading the transcripts, notes were taken and relevant sections were marked. Field notes by the researchers (LMK and MO) were summarized and linked to the corresponding sections. In the second stage, the initial codes were refined into categories, resulting in a list of code categories and descriptions (eg, the initial code "support in taking steps within one's own context" was categorized as 'support for implementing tailored lifestyle plans'). In the third stage, themes were derived from the codes (eg, the category 'support for implementing tailored lifestyle plans' was thematized as 'needs').[26]

Methodological Rigor

Various measures were implemented to enhance the trustworthiness of this study.[31] Throughout the research process, reflexivity enhanced the credibility and confirmability of the data. Bracketing was used to identify and address the researcher's biases, personal beliefs, and assumptions.[32] Additionally, memo-taking was employed throughout all stages to document the researcher's reflections, outline initial themes, and detail the context of the interviews. Building rapport with participants during interviews was prioritized to foster trust and openness, essential for collecting rich data.[33] This was achieved by assuring participants there were no incorrect answers. Data analysis was conducted by LMK and peer-reviewed by MO. Finally, the qualitative data were transparently analyzed using a grounded theory analysis strategy.

Results

Narrative Review

The database searches yielded 174 unique results, of which four review studies were eventually included in the narrative review.[12,13,16,19] The participants in these reviews included adults with conditions such as rheumatic diseases, cancer, chronic kidney disease, type 2 diabetes mellitus, chronic obstructive pulmonary disease (COPD), obesity, and heart failure, as well as HCPs responsible for their care. The narrative review identified several needs, barriers, and facilitators related to self-management and self-management support (Figures 2 and 3).

Data showed that people with chronic diseases have specific needs for self-management, including open and honest communication, emotional and individualized support, peer contact, and tailored information (Figure 2). Barriers such as generic recommendations, limited knowledge and skills, psychological distress, stigma, and unrealistic expectations can hinder self-management efforts. Practical challenges, such as time constraints, ingrained habits, and dissatisfaction with

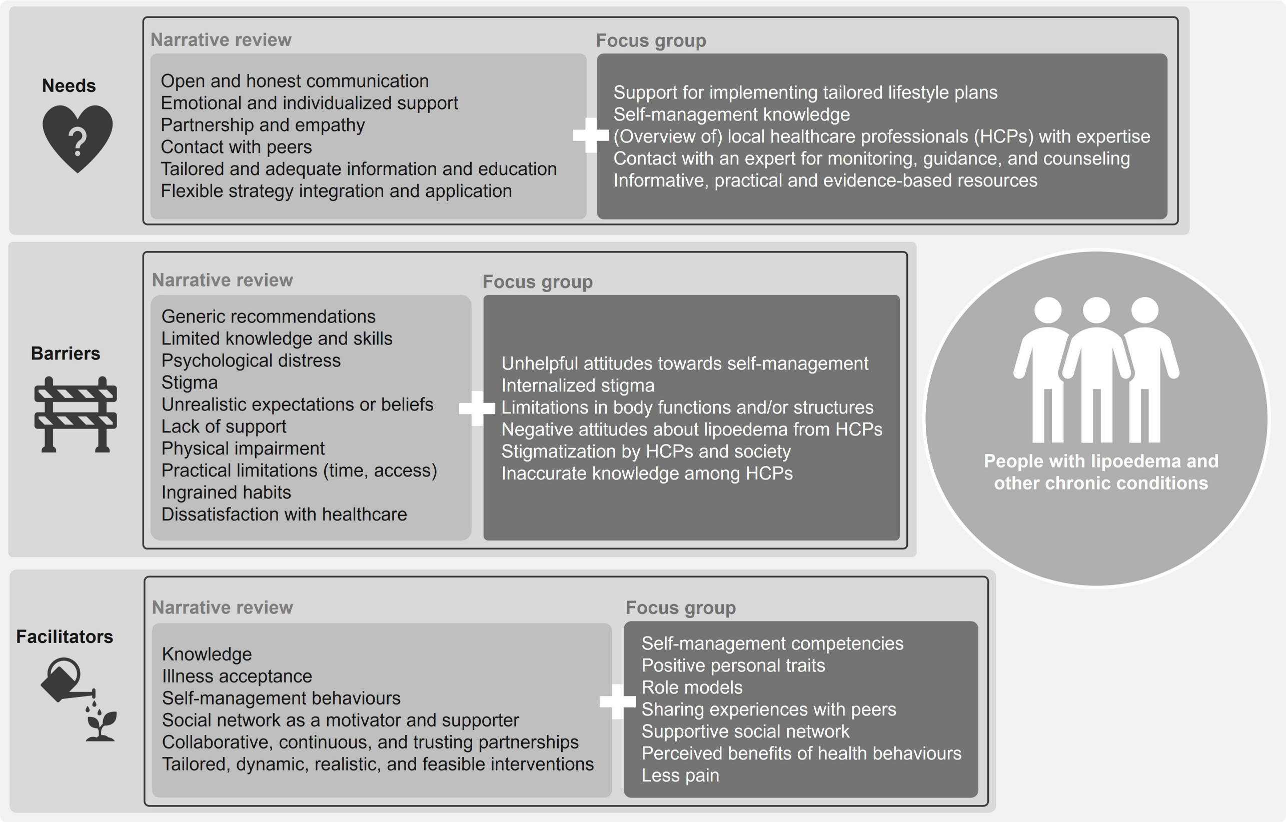

Figure 2 Needs, barriers, and facilitators for self-management in people with lipoedema and those with other chronic conditions, as experienced by people with lipoedema and other chronic conditions, identified through the narrative review and focus group.

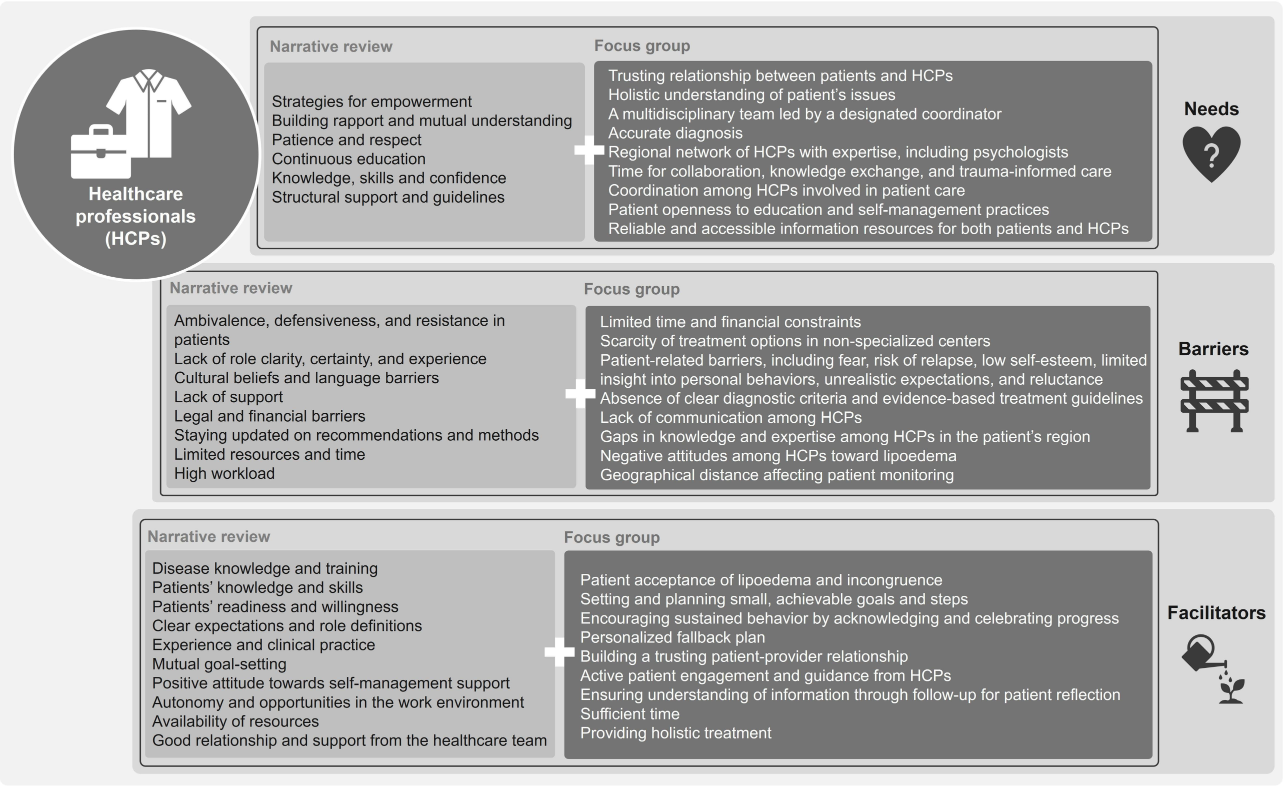

Figure 3 Needs, barriers, and facilitators from healthcare professionals (HCPs) regarding self-management support for people with lipoedema and other chronic conditions, identified through the narrative review and focus group.

healthcare further limit progress. Facilitators that promote successful self-management include knowledge, illness acceptance, self-management behaviors, and a strong social support network.

Data from HCPs highlighted various needs, barriers, and facilitators for supporting self-management (Figure 3). Needs include strategies for empowerment, building rapport and mutual understanding, and sufficient knowledge, skills, and guidelines. Barriers include patients' ambivalence, defensiveness, resistance, and a lack of support, experience, resources, and time. Facilitators include, among others, the knowledge and skills of both patients and HCPs, patient readiness and willingness, and mutual goal-setting. Additionally, a positive attitude toward self-management support, autonomy, opportunities in the work environment, and strong relationships within the healthcare team enhance self-management support.

Focus Group with People with Lipoedema

The focus group, which included five women with lipoedema (ages 32 to 53), revealed specific needs, barriers, and facilitators related to self-management of lipoedema (Figure 2). All invited participants ultimately participated in this study.

Needs

Participants expressed a strong need for support in integrating lifestyle changes into their daily routines. They felt that after receiving their diagnosis, they were left to navigate the process of integrating lifestyle guidelines on their own, with one participant stating:

> It's indeed very nice that you get the guidelines, but then again, it really is just "figure it out yourself". That's what it really comes down to. (Participant 3)

They also experienced a need for more personalized guidance and coaching, with one suggestion being a "lipoedema coach" to help with practical steps, such as referrals to appropriate HCPs and assistance with implementation:

> A kind of lipoedema coach, so to speak, who would say to you: "Hey, this step, this step, and in your area, you can go to that physical therapist. That dietitian understands it, and if your general practitioner doesn't understand, then we can call your general practitioner", you know, things like that. (Participant 4)

Additionally, participants emphasized the need for regular contact with HCPs for monitoring, guidance, and counseling, as expertise on lipoedema is often lacking in their local area:

> In our own area, there is just basically no one. There is just no one. If there were more expertise in other parts of the country, where you could, for example, go, I think it would be a lot easier. (Participant 3)

Furthermore, participants expressed a need for a nationwide overview of HCPs with expertise in lipoedema, along with informative, practical, and evidence-based resources. Another important issue raised was the lack of knowledge about lipoedema among HCPs. One participant shared her frustration on this matter:

> I would really like other people to be informed as well. Because I also went to the dietitian for this. Well, I went there that time and then left. I think, you don't understand anything about it. (Participant 1)

Other identified needs include knowledge on how to best manage lipoedema and its associated challenges, as well as support in maintaining positive behavioral changes over time.

Barriers

The focus group also highlighted various barriers that hinder their self-management. Participants reported stigmatization by society, even by HCPs, and self-stigma to hinder their self-management. One woman explained how stigma made her avoid fitness centers and one participant explained the feeling that her general practitioner made her feel like it was her own fault and that he does not believe in lipoedema:

> Then I go to my general practitioner, and he says: "Oh no, I don't believe in that. You just need to exercise more", and then he said: "Yeah, sometimes people say, I walk 10,000 steps a day, and I say, walk 20,000". (Participant 4)

Inaccurate knowledge from HCPs also plays a significant role in discouraging the participants, as some participants experienced oversimplified advice about weight loss:

> She kept saying that if you ate little enough […] then you would lose weight and you'd see it in your legs too. And I think, yeah, I've already explained a few times that maybe it will happen a little, but not to the extent she claims, and she shouldn't use that as motivation because it's really not motivating. (Participant 1)

Barriers also exist due to HCPs negative attitudes as one participant recounted her experience of being dismissed by a surgeon during an unrelated medical procedure:

> So when I asked the surgeon, "what effect will that have on my lipoedema?" He said: "Hm, oh lipoedema, yeah, but we don't believe in that" I think, yeah, we don't believe in it… It's not a religion. It's just, this is just a medical thing. (Participant 4)

Other barriers were more personal, including the perceived attitude toward self-management, with participants feeling that too much responsibility is placed on them without sufficient external support. One participant expressed frustration, saying:

> So it's always focused on: how do you manage it yourself? What are you doing about it? Then I think, yeah, why don't you guys do something about it, huh? […] I'm doing my best, but I'm not solving it. (Participant 4)

Similarly, another participant shared how the term "self-management" itself evokes a sense of burden. Other personal barriers include physical limitations caused by lipoedema or comorbid conditions, which restrict the ability to engage in exercise for instance.

Facilitators

In addition to the facilitators identified in the review, participants in the focus group with women with lipoedema highlighted several factors that support their self-management. A key facilitator is having the appropriate self-management competencies. One participant, for example, emphasized the importance of the ability to make practical adjustments to daily routines to manage energy levels and prevent exhaustion:

> …So, for example, improving your condition, but on the other hand, it's also, for instance, taking that one break or sitting down, eating calmly […] to make sure I can get through the day more steadily. (Participant 5)

Other important competencies include the ability to measure what works and what does not work, integrating lifestyle activities into daily life, managing stress, and finding the right moments for activities, all of which helped participants to better manage their lipoedema. Personal traits like perseverance and the ability to stay positive also play a crucial role in dealing with the challenges of lipoedema. One participant shared her determination to remain active despite the pain:

> Perseverance, I think, is very important. Because, yeah, sometimes I'd rather just lie on the couch all day or stay in bed, because then I don't feel pain. I don't feel the heaviness, so that's just the most comfortable. But that's not an option. (Participant 2)

Role models, often found online, were another source of motivation. Participants felt empowered by following people who share their experiences with lipoedema and demonstrate positive strategies. Sharing experiences with peers also emerged as a strong facilitator, offering emotional support and practical advice. One participant noted the value of connecting with others to share experiences:

> I think if you have peers, it's always easier. I think it's always better to share experiences, right? Because that way someone else can help you, but you can also help someone else. (Participant 3)

A supportive social network, where family and friends understand and can explain lipoedema, also contributes to self-management, helping to combat stigma in their environment. Finally, the perceived benefits of health behaviors are a facilitating factor in self-management. One participant mentioned how wearing compression garments helped reduce her symptoms throughout the day, while another participant explained that as exercising became easier, her chronic pain diminished, encouraging her to continue:

> And exercising is just going better and better, right? I have less and less chronic pain, so you can increase it, and that's really nice to do. (Participant 5)

Focus Group with HCPs

Focus group findings from a meeting with five HCPs, including (oedema) physical therapists, a dermatologist, and a dietitian experienced in working with people with lipoedema, highlighted key needs, barriers, and facilitators for supporting self-management in the lipoedema population. Three of the HCPs worked in medical facilities, while two worked in private practices. All but one of the potential participants invited to participate in this study ultimately participated. The reason for this HCP's non-participation was scheduling conflicts.

Needs

Key needs for improving self-management support include establishing a trusting relationship with patients and encouraging their openness to self-management (Figure 3). One HCP observed a sense of disappointment among people with lipoedema due to their complaints being misunderstood by HCPs for years, leading to reluctance in seeking further contact:

> If you, and I see that quite often, people are a bit hesitant in the beginning. So, yeah, I think you first need to build a trusting relationship with someone. Someone needs to really be open. […] For me, it's really important to check that carefully. (HCP 4)

HCPs also emphasized the importance of using a holistic approach to identify all factors influencing the patient's well-being to determine where modifiable factors exist and where treatment can make a difference. This helps in accurately identifying the issues someone is struggling with:

> You really need to go through the bio-psycho-social model with someone with lipoedema to see where the modifiable and winning factors are. And I think that you should also look at the diagnosis… Why is someone struggling, actually asking that question from a broader perspective. (HCP 3)

HCPs further highlighted the need for regional multidisciplinary networks with expertise in lipoedema and clear leadership within these teams. One HCP mentioned that, in her ideal world, she would work in a multidisciplinary center with experts. In addition, there was an expressed need for the involvement of psychologists in treating these individuals, as there is much to gain in addressing their psychological well-being. Another HCP added that, depending on the individual's needs, a "captain" should lead the multidisciplinary team once a proper diagnosis has been made. She stated:

> There isn't really one captain of the ship, I think. […] I think a proper diagnosis needs to be made […] and then it depends on the patient who becomes the captain, right? (HCP 5)

One HCP expressed the need for a knowledge-sharing network to improve care and the time to engage in it:

> If I look at it from a professionals' perspective, I would need more time in my work schedule to seek collaboration with other care professionals and exchange knowledge. (HCP 3)

Additionally, there is a need for reliable information for both patients and HCPs, as a significant amount of misinformation is currently available. This often leads to people selecting information that aligns with their personal preferences.

Barriers

Barriers to self-management support identified by HCPs include several patient-related challenges, such as a lack of insight into their behavior, unrealistic expectations, relapse in behavior changes, and reluctance stemming from negative past experiences with healthcare. Other patient-related barriers mentioned by HCPs include fear and low self-esteem in individuals and externalized self-image:

> This group has somewhat lower self-esteem. I find this comes up more than average. […] Yes, and also people who may seek external validation, perhaps a bit more than average. (HCP 3)

HCPs also highlighted barriers to collaboration between HCPs, with one HCP noting that the various disciplines involved often cannot communicate effectively, as they do not work within a team. Also, the absence of treatment options in non-specialized and multidisciplinary centers creates significant barriers to supporting self-management. Another barrier identified by HCPs is the difficulty in monitoring patients over time, particularly when people reside further away from them. Additionally, insufficient knowledge and expertise among HCPs, leading to the application of incorrect treatments, is a significant barrier to providing adequate self-management support:

> I now have to refer them to a paramedic somewhere in the region. And then I see that completely different things happen than what I had intended. And ultimately, especially with diagnostics, it's challenging, particularly when people go to an oedema therapist in the region and end up receiving all kinds of things I hadn't requested. (HCP 5)

Another barrier mentioned was the negative attitude towards lipoedema among HCPs. HCPs reported that general practitioners and even dermatologists often claim they do not believe in the existence of lipoedema:

> I have a general practitioner in my work area who insists that lipoedema does not exist. (HCP 1)

Furthermore, the absence of evidence-based treatment guidelines and clear diagnostic criteria further hinders self-management support:

> We have to work with what we can gather ourselves from studies. Yes, and with our common sense and mostly practice-based knowledge, but there is little that is evidence-based. (HCP 1)

Facilitators

HCPs highlighted several facilitators that help improve self-management support for people with lipoedema. A primary factor was patient acceptance of the lipoedema diagnosis and body incongruence. One HCP noted that patients who accept their condition are often better equipped to manage it independently, compared to those who may only recently have become aware of it:

> Because they are actually reassured by it. And they're okay with having lipoedema, okay with their incongruence, and very capable of applying self-management. But then there's the group that has complaints. Yes, they want symptom relief. They come in with a completely different request for help. (HCP 2)

Another facilitating factor was using follow-up sessions to confirm patients' understanding and retention of information. Repetition and review were seen as crucial in ensuring that information is well understood and applied effectively:

> But I always make a follow-up call afterwards. And then I go over it again because it's often a lot of information they get at once. (HCP 5)

HCPs also emphasized the importance of setting small, achievable goals to build patients' confidence in managing their condition. This approach allows patients to feel that progress is attainable, encouraging them to move forward:

> But we keep the first steps fairly small. So, a small goal in daily life that's achievable. It's mainly achievable. People often think too big or don't dare at all. […] And confidence, I think, comes from taking steps and daring to take steps again. (HCP 3)

Additionally, recognizing and celebrating progress, no matter how small, was considered essential for maintaining motivation and commitment to self-management. Developing personalized fallback plans was another facilitator, as was fostering active patient engagement. HCPs highlighted the importance of adopting the right role as a HCP, focusing on empowering the patient rather than stepping into a "rescuer" role:

> If your patient starts behaving like a victim, then you become the rescuer, so to speak. So, what role does your own attitude play? (HCP 2)

Lastly, participants emphasized the need for a holistic treatment approach and sufficient time during consultations to fully understand the biopsychosocial aspects of the patient's condition and individual challenges:

> It's mostly that broad aspect, that biopsychosocial aspect, that makes it so hard to pick out in a very short conversation what's the win-factor for that person, but you really need time for that. (HCP 3)

Discussion

The aim of this study was to conduct a comprehensive needs assessment to improve self-management by exploring the needs, barriers, and facilitators related to self-management and support for people with lipoedema and the HCPs involved in the care for people with lipoedema. People with lipoedema identified a need for support in implementing lifestyle plans, access to experts for guidance and counseling, and informative, evidence-based resources. They encounter barriers, including a lack of awareness, knowledge, and expertise among HCPs, as well as high levels of stigmatization by society and their HCPs. Key facilitators included self-management competencies, supportive networks, perceived benefits of health behaviors, and access to role models. Specific challenges for HCPs treating people with lipoedema included communication difficulties and barriers when collaborating with other HCPs due to a lack of specialized professionals and centers in their regions. Additionally, negative attitudes towards lipoedema among HCPs further hinder effective self-management support. They expressed a need for multidisciplinary teams, accurate diagnosis, patient openness, and reliable information resources. Facilitators included fostering trust, encouraging patient participation, and setting achievable goals.

We found parallels between the experiences of people with lipoedema and those with other chronic conditions. While each population has unique characteristics, notable similarities in self-management needs, barriers, and facilitators across both groups were identified. Common factors influencing self-management included the need for tailored information and ongoing support. Both populations face challenges such as limited knowledge, self-management skills, and psychological or emotional difficulties. Additionally, the focus group and the narrative review with HCPs identified overlapping needs, barriers and facilitators in supporting self-management. These included the need to build trust, as well as increased knowledge and expertise among both HCPs and people with lipoedema. Shared facilitators included role clarity, while common barriers included limited time and resources.

A key finding from this study is the communication issues experienced not only among HCPs, but also between HCPs and patients. Both people with lipoedema and their caregivers report a lack of knowledge among HCPs, as well as negative attitudes towards the condition, which likely affects the quality of their relationships. Studies involving people with multiple chronic conditions have shown that positive perceptions of the patient-HCP relationship are associated with improved self-management, reduced treatment burden, and better psychosocial outcomes.[34] Furthermore, studies indicate that individuals who trust their HCPs, feel that sufficient time is spent on their care, and believe they are being listened to tend to adhere better to treatment plans.[34,35] Self-management is not an isolated process but is shaped by relationships with others, including HCPs, and relies on both patients' willingness and ability as well as the positive attitudes and appropriate skills of their HCPs.[36,37] The need for peer contact, guidelines, and sufficient consultation time identified in this study echoes other research findings on chronic illness self-management.

People with lipoedema in this study faced additional challenges influencing their self-management compared to the chronic population studied in the narrative review. One factor contributing to this may be that the lipoedema population is exclusively female. A systematic review on diabetes self-management highlighted that being female was often associated with challenges in self-management.[38] This may be explained by higher obesity rates among women compared to men,[39] which could be attributed to lower participation in physical activity and limited time for exercise or self-care, as women are three times more likely than men to engage in unpaid caregiving responsibilities.[40–43]

Additionally, high levels of stigma experienced by people with lipoedema may also contribute to these influencing factors. Our recent study on lipoedema functioning found that participants faced high levels of stigma from HCPs and society, as well as internalized stigma.[44] Similarly, a study on people with type 2 diabetes found that those experiencing stigma were less likely to engage in self-management.[45]

Strengths and Limitation

This study has several strengths. Firstly, it is the first study to combine a narrative review and focus groups with both people with lipoedema and their HCPs, providing a comprehensive understanding of self-management needs, barriers, and facilitators while addressing the complex nature of self-management. By combining existing literature with qualitative insights from patients and HCPs, the study revealed multiple dimensions of self-management and its support. Secondly, the findings from the narrative review informed the interview guide, ensuring that the questions were grounded in existing literature. Thirdly, data triangulation enhanced the study's credibility and validity by ensuring cross-verification of the results.

However, several limitations should be acknowledged. Firstly, due to the absence of research on self-management in lipoedema, the narrative review was based on studies in patients with chronic conditions in general. Therefore, the applicability of findings from these broader studies to the lipoedema population may be limited. While some findings may not fully apply to people with lipoedema, the researchers mitigated this by excluding disease-specific factors and consulting an independent researcher and physician. Secondly, while online focus groups enabled broader geographic participation, the virtual setting may have limited participants' ability to share experiences. However, this is unlikely to have affected the richness of the data, as each participant appeared to share their contributions freely and contributed equally during the discussions, building upon each other's input. Thirdly, a convenience sample of patients from the ECL population, who may have a higher-than-average disease burden, was used to recruit focus group participants. This approach may limit the representativeness of our sample. However, by exclusively including individuals with a confirmed diagnosis and HCPs with expertise in lipoedema, we aimed to minimize the risk of self-diagnosis or misdiagnosis. Fourthly, data saturation was not pursued, and the relatively small focus group size may have limited the depth of insights. However, due to the mixed-methods approach, the study prioritized capturing diverse perspectives over achieving saturation. By focusing on the varied perspectives of self-management, the study provides valuable insights that contribute to the development of a tailored self-management intervention. Lastly, factors influencing self-management may have been classified differently by the two populations studied. For instance, a "need" identified by people with lipoedema may have been categorized as a "facilitator" in the narrative review, complicating the interpretation. However, the study's methodological rigor helped address this by ensuring balanced interpretations.

Implications

This study lays the groundwork for developing effective self-management interventions for people with lipoedema, while emphasizing the need for targeted training and resources for both patients and HCPs involved in their care. The similarities in self-management needs, barriers, and facilitators between people with lipoedema and those with other chronic conditions suggest that existing self-management strategies could be valuable if adapted to the specific needs of people with lipoedema and their HCPs. Additionally, the psychosocial and emotional challenges faced by people with lipoedema, such as internalized stigma and low self-esteem, underscore the importance of integrating psychological counselling into their care. To address these challenges, HCPs could consider incorporating psychoeducation or cognitive-behavioral therapy into their treatment plans, particularly in the absence of interventions specifically tailored to people with lipoedema. Special attention should be given to incorporating facilitators identified in this study, such as role models, peer support, and social networks, into self-management interventions. Enhancing illness acceptance should also be prioritized. Furthermore, the limited knowledge of lipoedema among HCPs and their unhelpful attitudes highlight the need for improved training and awareness. Specialized lipoedema training modules should be developed for HCPs, focusing on key elements such as empathetic communication, active listening, shared decision-making, patient readiness, and awareness of stigma and its effects. Improving communication between HCPs and fostering collaboration are also essential. This could include the development of regional consultation structures that engage HCPs with expertise. Additionally, efforts must be made to harmonize the general international guidelines for the treatment of lipoedema with regard to self-management, in the absence of specific self-management interventions. Both the American and European guidelines for lipoedema recognize the importance of self-management but differ in their approach.[8,9] The American guideline emphasizes a comprehensive daily self-care regimen, while the European guideline prioritizes evidence-based patient education and strategies to enhance self-efficacy through problem-solving.

Future research should focus on developing interventions that enhance both the self-management capabilities of people with lipoedema and the support provided by HCPs. Additionally, research should prioritize updating and aligning international perspectives on self-management to ensure consistency in treatment approaches and optimize care for people with lipoedema.

Conclusion

In conclusion, this study emphasizes the complex nature of self-management and the needs of people with lipoedema, along with the barriers and facilitators involved for both patients and their HCPs. People with lipoedema identified a need for support in implementing lifestyle plans, access to experts for guidance and counseling, and informative, evidence-based resources. They encounter barriers, including a lack of awareness, knowledge, and expertise among HCPs, and high levels of stigmatization both by society and by their HCPs. Key facilitators included self-management competencies, supportive networks, perceived benefits of health behaviors, and access to role models. Specific challenges for HCPs treating people with lipoedema include communication difficulties and barriers when collaborating with other HCPs due to a lack of specialized professionals and centers in their regions. Additionally, negative attitudes towards lipoedema among HCPs further hinder effective self-management support. They expressed a need for multidisciplinary teams, accurate diagnosis, patient openness, and reliable information resources. Facilitators included fostering trust, encouraging patient participation, and setting achievable goals.

This study underscores the need for tailored self-management interventions for people with lipoedema, addressing both the physical and emotional aspects of the condition. Additionally, improving HCPs' knowledge through specialized training, fostering empathetic communication, and promoting collaboration are essential steps to enhance self-management support for people with lipoedema. The narrative review revealed parallels between the experiences of people with lipoedema and those with other chronic health conditions, highlighting the value of adapting existing self-management strategies from other chronic conditions to meet the specific needs, barriers, and facilitators relevant to people with lipoedema and their HCPs. Efforts should also be made to update and align international self-management perspectives and guidelines to ensure consistent treatment and optimized care.

Ethics Approval and Consent to Participate

The study was conducted according to the principles of the Declaration of Helsinki.[46] Recruitment and data collection started subject to approval of the study by the Hanze Ethics Advisory Committee (approval number: heac.T2024.026) and Nij Smellinghe hospital's local feasibility committee (reference: 26906/JB/AB).

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Disclosure

The authors report no conflicts of interest in this work.

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