



UMEÅ UNIVERSITY

Lipoedema

- Lived Experiences, Functional Performance,
and Psychological Well-Being in Affected
Women

Johan Dahlberg

Academic dissertation

Which, with the due permission of the Vice-Chancellor of Umeå University for
the examination for the Degree of Doctor of Medical Science, is presented for public defence in

Sal A, Byggnad 1D, plan 9, NUS on Thursday, 4 June, 2026 at 09:00.

Link to participate via Zoom: <https://umu.zoom.us/j/62878331943>, password: 112233.

The thesis will be defended in Swedish.

Faculty opponent:

Docent Malin Olsson

Institutionen för vårdvetenskap, Marie Cederschiöld högskola,
Stockholm, Sverige

Department of Public Health and Clinical Medicine
Dermatology and Venereology

Organisation

Umeå University
Department of Public Health and
Clinical Medicine
Dermatology and Venereology

Document type

Doctoral thesis

Date of publication

13 May 2026

Author

Johan Dahlberg

Title

Lipoedema: - Lived Experiences, Functional Performance, and Psychological Well-Being in Affected Women

Abstract

Background: Lipoedema is a chronic condition that predominantly affects women, characterised by an accumulation of adipose tissue in the extremities, accompanied by pain, a sense of heaviness, and easy bruising.

Aim: This thesis aimed to explore the lived experiences of women with medically verified lipoedema, including everyday lives and healthcare interactions. We also evaluated muscle strength, physical capacity, body composition, health-related quality of life, perceived stress, anxiety, self-compassion, perfectionism, and impostor phenomenon.

Methods: This thesis comprises five papers with both qualitative and quantitative approaches. In *Paper I*, a Priority-Setting Partnership was utilised within a national design to identify research questions prioritised by participants with lived experience of lipoedema and clinicians. *Papers II and III* used qualitative methods, collecting data through 12 semi-structured interviews with women with a verified lipoedema diagnosis. The transcripts were analysed using qualitative content analysis to yield both manifest and latent content. In *Paper IV*, data were collected by measuring isometric strength and physical capacity in 18 women with lipoedema and by evaluating body composition using dual-energy X-ray absorptiometry as well as validated questionnaires to assess health-related quality of life, alcohol use, and physical activity. In *Paper V*, psychometric instruments were used in combination with RAND-36 to screen 18 women with lipoedema for signs of anxiety, stress, impostor phenomenon, perfectionism, self-compassion, and health-related quality of life.

Results: *Paper I:* Ten research questions were prioritised by representatives from individuals with the lived experience of lipoedema and clinicians. These ten questions comprised two tiers, encompassing diagnostic methods, treatments, and treatment outcomes. *Papers II and III:* Two themes emerged: “An uncertain uphill battle against a divergent body and societal ignorance” and “Pushing the barricaded doors to treatment and care while fighting to illuminate the shadows of lipoedema”. In *Paper II*, the women described how the condition made them feel trapped within their bodies and limited in their day-to-day activities. They also described social exclusion, while highlighting that emotional support from family and friends was an important aspect of their lives. In *Paper III*, their experiences of healthcare varied, but most were negative, characterised by limited or no support and treatment, disbelief, and being labelled obese by healthcare professionals. Financial limitations, varied treatment experiences, and a search for something that would alleviate their symptoms were also described. *Papers IV and V:* In *Paper IV*, isometric strength and muscle mass according to DXA were unimpaired. The 30-second sit-to-stand test resulted in fewer repetitions performed, while the 6-minute walk test did not yield any deviation in distance. However, the participants experienced increased pain at completion of the 6-minute walk test. In *Paper V*, RAND-36 results showed lower scores across all subscales regarding quality of life. The subscales of role physical, role emotional, pain, and energy/fatigue displayed the lowest scores. There were signs of stress among one-third of the participants, but self-compassion scores were high: 88.9% (n=16) reported moderate to high self-compassion.

Conclusion: Lipoedema significantly reduces the health-related quality of life and physical and mental well-being of women. Women’s experiences of healthcare indicate that knowledge of lipoedema in healthcare is limited, a lack of evidence-based care constrains women’s access to effective interventions, and substantial research gaps persist. The absence of objective diagnostic methods undermines clinical management and research comparability, making the development of such methods a critical priority. Education for healthcare professionals on lipoedema, large multicentre studies of treatments, and the implementation of interventions in healthcare settings are all necessary to reduce the consequences of lipoedema and provide women with lipoedema care and support. The findings in muscle strength, physical capacity, and body composition do not account for the symptoms described by participants and suggest that these symptoms are attributable to pain and adipose tissue accumulation. Objective and subjective perspectives should both be integrated in lipoedema consultation and treatment. The psychometric findings differ between the qualitative studies and the rated health-related quality of life. It is imperative to consider protective psychological factors when planning lipoedema interventions.

Keywords: Lipoedema, women’s health, research priority, content analysis, patient experience, quality of life, muscle strength, DXA, self-compassion

Language

English

ISBN

978-91-8070-980-4 (print)
978-91-8070-981-1 (pdf)

Number of pages

61 + 5 papers