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RESEARCH ARTICLE



A qualitative study exploring the experiences of individuals living with lipoedema and the impacts it has on their quality of life

Rhiannon Stellmaker^a , Belinda Thompson^a , Vincent Singh Paramanandam^a ,
Kerry A. Sherman^b , Helen Mackie^a  and Louise Koelmeyer^a 

^aAustralian Lymphoedema Education, Research and Treatment Centre (ALERT), School of Health Sciences and Nursing, Faculty of Medicine, Health and Human Sciences, Macquarie University, North Ryde, NSW, Australia; ^bLifespan Centre for Health and Wellbeing, School of Psychological Sciences, Levels 2 and 3, 16 University Ave, Macquarie University, North Ryde, NSW, Australia

ABSTRACT

Purpose: Individuals with lipoedema may experience negative impacts that are not often identified through current quality-of-life measures. The aim of this study was to explore the experiences of individuals living with pre-existing lipoedema and their perceptions of how these experiences influence quality of life.

Methods: Participants with a prior diagnosis of lipoedema participated in a single semi-structured interview or focus group. These interviews/focus groups were transcribed verbatim, allowing for an inductive thematic analysis to be conducted.

Results: Sixteen participants were included and four main themes were identified. These included: the ongoing work of living with lipoedema, living with a restrictive and overwhelming condition, caught between self-acceptance and social judgement, and forced to navigate lipoedema alone. Across the four themes, 21 sub-themes emerged to convey the quality-of-life concerns experienced by individuals with lipoedema.

Conclusions: Individuals living with lipoedema experience impacts on their quality-of-life across physical, psychological, and social aspects of life. This study highlights how the ongoing burden of physical symptoms, social perceptions, and healthcare-related challenges contributes to reduced quality-of-life for individuals living with lipoedema. Increased knowledge and awareness amongst healthcare providers is needed to improve care received by individuals living with this condition.

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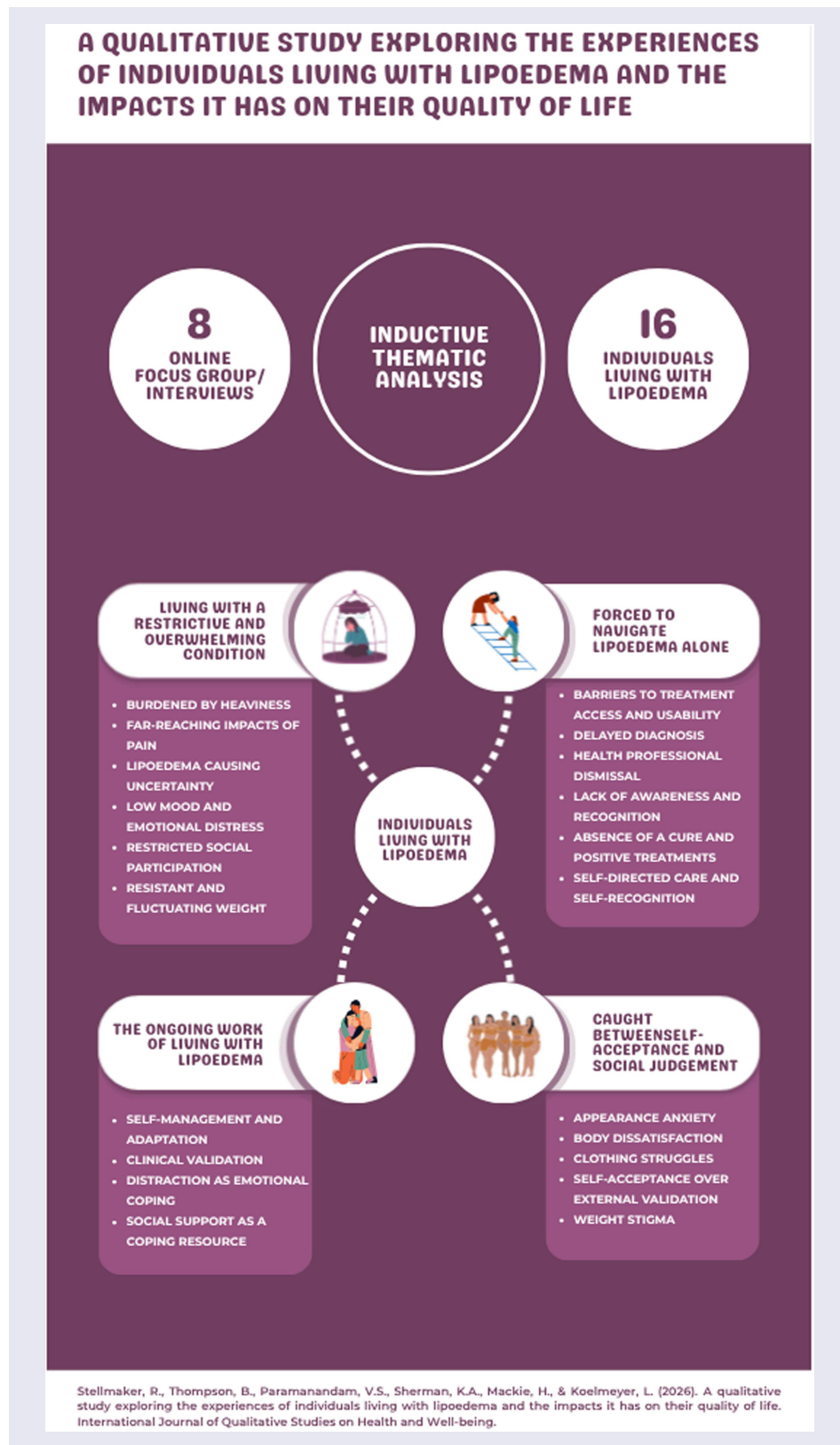
Lipoedema; quality of life; qualitative research; weight stigma; healthcare experiences; psychological well-being; social participation

CONTACT Rhiannon Stellmaker  rhiannon.stellmaker@mq.edu.au  Australian Lymphoedema Education, Research and Treatment Centre (ALERT), School of Health Sciences and Nursing, Faculty of Medicine, Health and Human Sciences, Macquarie University, North Ryde, 2109, NSW, Australia

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Introduction

Lipoeidema is a chronic condition characterized by the painful disproportionate adipose tissue in the bilateral legs and sometimes arms of an individual (Bertsch et al., 2020). Women are almost exclusively

affected, with hormonal changes including puberty, pregnancy and menopause thought to influence the onset of the condition (Bertsch et al., 2020). Lipoedema currently does not have a definitive diagnostic criterion; therefore, identifying its prevalence is difficult (Czerwińska et al., 2022; Forner-Cordero et al., 2025; Kloosterman et al., 2023). Lack of a diagnostic criterion causes lipoedema to often be confused with lymphoedema and/or obesity, resulting in incorrect treatments and clinical care, having a negative impact on the individual's quality of life (QoL) (Bertsch et al., 2020; Czerwińska et al., 2022; Forner-Cordero et al., 2025).

The World Health Organization (WHO) defines QoL as “an individuals' perception of their position in life in the context of the culture and value systems in which they live and relation to their goals, expectations, standards and concerns” (The WHOQOL Group, 1998, p.551). This definition recognizes QoL as a multi-dimensional construct encompassing physical, psychological, social and environmental aspects of life (Ranganathan et al., 2025). Consistent with the WHO International Classification of Functioning, Disability and Health (ICF), which recognizes functioning of an individual with health conditions to be an inclusive term for body functions, body structures, activities and participation (de Schipper et al., 2015; Kloosterman et al., 2023; World Health Organisation, 2001). Therefore, exploring QoL may help identify the physical, psychological, social and environmental impacts experienced by individuals living with lipoedema.

Previous research demonstrates that lipoedema affects multiple dimensions of QoL. The excess weight carried by an individual in their lower body can make completing daily activities difficult due to the impacts of physical symptoms, such as pain and heaviness (Kloosterman et al., 2023; van Esch-Smeenge et al., 2017). Individuals living with lipoedema may also experience psychological challenges associated with uncertainty surrounding lipoedema aetiology and conflicting healthcare advice (Falck et al., 2025a). Previous studies have identified that altered body shape and limited awareness amongst healthcare professionals may contribute to reduced emotional wellbeing and overall QoL (Christoffersen & Tennfjord, 2023; Dahlberg et al., 2025; Dudek et al., 2016; Falck et al., 2025a; Kloosterman et al., 2025; Melander et al., 2022; Romeijn et al., 2018). Additionally, overall QoL is impacted as individuals living with lipoedema have reported reduced participation in social activities (Christoffersen & Tennfjord, 2023; Czerwińska et al., 2021; Dahlberg et al., 2024; Kloosterman et al., 2025; Melander et al., 2022). Challenges accessing appropriate care and support may further contribute to these impacts on QoL.

A recent study comparing the health-related QoL between females with bilateral lower limb lymphoedema and lipoedema found that, those diagnosed with lipoedema reported a greater frustration with insurance coverage than those with lymphoedema (Stellmaker et al., 2026). In Australia, access to funded treatment options remains limited, with individuals often facing substantial out-of-pocket costs (Stellmaker et al., 2026). The absence of a universally accepted diagnostic criterion and limited awareness of lipoedema may contribute to delayed diagnosis and access to appropriate care. Consequently, these factors may influence how individuals experience and manage living with lipoedema within Australia.

While previous quantitative and qualitative studies have demonstrated that lipoedema affects physical, psychological and social aspects of health, there is limited research exploring the experiences of Australians living with a confirmed lipoedema diagnosis. Recent qualitative studies have explored the experiences of individuals living with lipoedema in European countries (Christoffersen & Tennfjord, 2023; Dahlberg et al., 2025; Falck et al., 2025b; Kloosterman et al., 2025; Melander et al., 2022). Given differences in healthcare accessibility, treatment and recognition, further research is needed to understand how individuals in Australia perceive the physical, psychological, and social impacts of lipoedema on their QoL. Therefore, the purpose of this study was to qualitatively explore the experiences of individuals living with pre-existing lipoedema and their perceptions of the impact of lipoedema on QoL. It is hoped that insights into individuals' experiences and current unmet needs will inform future research direction and guide clinical care of lipoedema.

Methods

Participant eligibility

Participants must have been diagnosed with lipoedema at the Australian Lymphoedema Education, Research and Treatment Centre (ALERT), at Macquarie University. A lipoedema diagnosis was undertaken

by experienced rehabilitation specialists and confirmed by the symmetrical enlargement of nodular adipose tissue of the lower limbs, excluding the feet (Mackie et al., 2023). At least two of the following secondary criteria must have been present for a lipoedema diagnosis: pain or tenderness in the legs; a family history of lipoedema; non-pitting swelling in the legs assessed by firm thumb pressure for 30 s; easy bruising of the legs (Mackie et al., 2023). The type and stage of lipoedema was classified using the Wounds UK Best Practice Guidelines (Wounds UK, 2017). Participants must also have been 18 years or older and female at birth. Participants were not eligible if they had a lymphoedema diagnosis alongside lipoedema or were unable to read or understand English. Although lipoedema and lymphoedema can coexist, individuals with lymphoedema were excluded to ensure the experiences explored in this study were specific to lipoedema. The Human Research Ethics Committee at Macquarie University, Sydney, Australia (No. 520241604160254) and MQ Health Clinical Research Executive for Governance Authorization (Ref MQCRG2025019) granted ethical approval for this study. This study was conducted in accordance with the National Statement on Ethical Conduct in Human Research and the Declaration of Helsinki.

Participant recruitment

During June 2025, participants on the ALERT Centre research database who had consented to be contacted for research were emailed study invitations. Participants were sent a link to an online screening form via REDCap electronic data capture tool (Harris and Taylor, 2019; Harris et al., 2009). If eligible, participants were prompted to complete the Participant Information and Consent Form and were required to provide written informed consent prior to participation. Participants who consented then completed a demographic survey. The study invitation was sent to 116 individuals, of which 39 completed the online screening form. Three participants were not eligible due to having a lymphoedema diagnosis along with lipoedema and two participants did not consent to participate, resulting in 22 individuals who provided written informed consent. Participants were contacted via email or phone to organize a suitable time for an online focus group/interview. Six participants later withdrew from the study or could not be contacted to organize an online interview.

Focus groups/interviews

Between June and July 2025, eight sessions were held via Microsoft Teams. Participants took part in a single data collection session, which was conducted as either a single-participant interview or a small focus group of two to three participants. The timing and format of the sessions depended on participant availability. The sessions followed a semi-structured format allowing for detailed exploration of the participants' lived experiences with lipoedema. A semi-structured interview guide (Supplementary material 1) was developed based on the available literature, existing QoL patient-reported outcome measures, and results from a previous QoL study (Morgan Brett & Wheeler, 2022; Stellmaker et al., 2026). It consisted of open-ended questions relating to diagnosis and management, feelings and mood, physical function, and symptoms, allowing exploration of the physical, psychological, social, and environmental impacts of living with lipoedema. The questions were accompanied by an array of prompts to deepen the data collection if required. This semi-structured interview guide was used by RS who had completed training on how to conduct a qualitative interview prior to the sessions. Each session was accompanied by a second researcher (BT, LK, or VSP). Interviewers were not involved in the clinical care of the participants, to support open disclosure. During the sessions, participants were encouraged to speak freely and provide information they felt was relevant to their experiences. Before concluding the sessions, participants were asked if there were further experiences they wished to discuss, to ensure all experiences were captured. Once the session concluded, researchers made notes on common themes mentioned throughout each session. The online sessions took between 45 and 80 min to complete.

The online sessions were recorded via Microsoft Teams. Microsoft Teams automatically generated written transcripts, which were subsequently checked by RS and BT against recordings and corrected for accuracy. All names and identifiable data were removed from the written transcripts and participants were given a unique number. Transcripts were de-identified by RS and checked further by BT.

Data analysis

Descriptive statistics were performed using the demographic surveys completed by participants, using JASP software (Version 0.16.4). Data were analyzed inductively using the six-step thematic analysis approach (Braun & Clarke, 2006). Two researchers (RS and BT) independently coded 25% of the transcripts during the initial stages of analysis. Coding interpretations were subsequently discussed to encourage reflective engagement with the data and consideration of alternative perspectives during theme development, rather than to achieve coding consensus (Braun & Clarke, 2019). Familiarization with the data involved reviewing interview recordings during transcript checking and repeatedly reading transcripts throughout the analysis process. Initial codes were generated inductively through line-by-line coding of the transcripts to identify meaningful aspects of participants' experiences. Following discussions of codes generated from the initial transcripts, the remaining transcripts were coded by one researcher (RS), using NVivo (version 14.0). Codes and themes continued to be reviewed and refined throughout the analysis process to ensure they accurately reflected participants' accounts. Codes were grouped according to shared patterns of meaning to generate candidate themes and sub-themes. Final themes and sub-themes were reviewed and refined through discussion between two researchers (RS and BT), with interpretations further considered by all authors.

Trustworthiness

Credibility was supported through a semi-structured interview approach characterized by active listening and the use of carefully worded, open-ended questions designed to minimize presuppositions, while allowing participants to elaborate and introduce experience they considered important. The first author (RS), whose research focuses on lipoedema, conducted the interviews and led the analysis. The research team comprised clinicians and researchers with expertise in lymphatic and adipose tissue disorders, rehabilitation medicine, psychology, patient-reported outcome measurement, and qualitative research. No researchers had a prior relationship with participants or lived experience of lipoedema. The researchers acknowledged that their professional interest in advancing knowledge and improving care for individuals with lipoedema may have influenced interpretation of the data. Reflexive field notes and post-session reflections were used to critically examine researcher positioning and emerging interpretations throughout data collection and analysis, with ongoing discussions among the research team to consider alternative perspectives (Elo et al., 2014).

Results

Participant characteristics

Sixteen women participated across eight focus groups/interviews. The age of participants ranged from 30 to 72 years, with a mean age of 46 years. Four participants reported a lipoedema arm diagnosis alongside their lipoedema leg diagnosis and 22 years was the average number of years participants had been living with lipoedema. The remaining participant characteristics are presented in [Table I](#).

When exploring the experiences of individuals living with lipoedema, four main themes were identified: the ongoing work of living with lipoedema, living with a restrictive and overwhelming condition, caught between self-acceptance and social judgement, and forced to navigate lipoedema alone. The four themes included 21 subthemes, conveying how lipoedema affects the physical, psychological, social and environmental aspects of life. Additional quotes for each theme are presented in supplementary material 2.

The ongoing work of living with lipoedema

Participants described living with lipoedema as an ongoing process of adaptation and self-management. Managing the condition required continual monitoring of symptoms, modification of daily activities, development of symptom relief strategies, and regulation of emotional responses. This often invisible work reflected the active efforts participants made to maintain physical function, social participation, and

Table 1. Participant characteristics.

Characteristics	Individuals with lipoedema (<i>n</i> = 16)
Age in years Mean (SD) [range]	46.4 (11.2) [30–72]
Average years living with lipoedema Mean (SD) [range]	22.1 (8.2) [8–35]
Gender	Frequency (number)
Female	100% (16)
State/territory	
NSW	93.75% (15)
ACT	6.25% (1)
Relationship status	
Partnered, living together	68.75% (11)
Single	31.25% (5)
Highest level of education	
Less than year 10	6.25% (1)
Vocational/trade qualification	31.25% (5)
University degree	62.50% (10)
Current employment status	
Student	6.25% (1)
Employed	81.25% (13)
Not currently working	12.50% (2)
Onset of lipoedema	
Puberty	56.25% (9)
Pregnancy	12.50% (2)
After surgery	6.25% (1)
Unsure	25.00% (4)
Lipoedema stage	
Stage 1	12.50% (2)
Stage 2	50.00% (8)
Stage 3	37.50% (6)
Lipoedema type	
Type I	12.50% (2)
Type II	37.50% (6)
Type III	50.00% (8)
Type IV*	25.00% (4)
Liposuction surgery for lipoedema	25.00% (4)
Currently receiving lipoedema treatment from a healthcare provider	31.25% (5)

n: number of participants; NSW: New South Wales, ACT: Australian Capital Territory; SD: standard deviation.

*Type IV lipoedema present concurrently with another lipoedema type.

emotional wellbeing, highlighting the considerable effort required to minimize the impact of lipoedema on QoL.

Self-management and adaptation

Participants described continually adapting their behaviours to manage the impacts of lipoedema and maintain participation in daily activities. Many modified how they completed everyday tasks due to symptoms of heaviness and fatigue, often taking additional breaks or altering activities to better accommodate their bodies. One participant identified struggling when completing errands: “I would like sit on the floor and do something or sit on a chair and do something or just take more breaks.” P2. These adaptations allowed them to complete tasks, however, participants reported that completing these tasks took longer than it would other individuals.

Participants also described an ongoing process of monitoring their bodily cues and adjusting their behaviours in response to symptoms. Managing lipoedema required constant awareness of physical limitations and careful balancing of activity levels. Most participants stressed that self-regulation was difficult “I do need to keep moving and so I find that moving does help a lot, but then the flip side of that is if I move too much then I'm doubled over in pain for the rest of the day.” P3. The unpredictable nature of symptoms required constant self-monitoring and decision-making, with participants continually adjusting their behaviour to reduce the impact of lipoedema symptoms.

Alongside these behavioural adjustments, participants actively engaged in a range of management strategies aimed at reducing symptoms and preserving function. Exercise, compression garments, vibration plates, weight-loss injections and liposuction were all reported as helping to alleviate symptoms for some individuals. Participants described benefits extending beyond symptom control, including improvements in mobility, daily functioning and psychological wellbeing. As one participant stated, “I know that my mental

health has gotten a lot better since I have been exercising.” P3, while another explained that symptom relief enabled increased participation in work, “I’m thankful that since I’ve been on the injections, a lot of that pain has been alleviated substantially, so I’ve increased hours at work.” P14.

Clinical validation

Participants described feelings of relief once they received a lipoedema diagnosis. With a confirmed diagnosis from a health professional, participants felt they were able to justify their need for more assistance or prove that they had been trying to reduce their weight. Participants finally felt they had an answer to symptoms they had been experiencing. One participant described, “It was like a massive weight had lifted off my shoulders, my head, my eyes. It was validation” P10. Some found it validating in terms of identifying what they had assumed “I was fairly certain myself that’s what it was already [lipoedema]. So, it’s kind of confirming something. You already know, just taken years to arrive to.” P15. Although some participants had already identified themselves to have lipoedema, they were still “overwhelmed, even though I knew, it was still overwhelming.” P5.

Participants found that receiving a diagnosis validated the management approaches they had independently implemented prior to diagnosis, making them feel they were looking after themselves correctly throughout all the uncertainty. One participant said, “So it was a huge life-changing experience to get diagnosed and a lot of the pain management, I had already been doing.” P10.

Distraction as emotional coping

Some participants described using distraction as a way of managing the emotional burden associated with lipoedema. Activities such as reading or watching television provided temporary relief from distressing symptoms and emotions, allowing participants to mentally disengage from the condition and regain a sense of emotional control. One participant explained, “I really want to hop into bed, not to sleep, but to read or do something just to get away from things and just turn off because I mean, feeling that real heaviness and the mood and the emotions are really running high. [...]. I just want to run away.” P4. Another participant agreed that distractions are a way of helping them cope with the emotional burden, “Watching trashy Netflix shows and stuff like that because it does work and it does make you feel so much better about yourself.” P3.

Social support as a coping resource

Participants expressed that support given by others allowed them to cope with lipoedema. Most were supported by their co-workers, friends, family, and significant other: “I have a very caring and respectful partner who loves me regardless.” P11. However, this support was not replicated across all participants. One participant reported, “I’m being told I can’t sit down at work, and I can’t do this. I can’t do that. Which is not true, but it makes trying to manage my condition much harder.” P16. Another stated in relation to their family, “So, from their perspective they’re like, well, it’s just all in your head. [...]. I’ve now received a diagnosis, so I don’t understand why you wouldn’t accept that and be a bit more supportive of it.” P9. This lack of support causes the participants to feel alone with trying to cope with life, living with lipoedema.

Living with a restrictive and overwhelming condition

This theme captures how lipoedema imposed a cumulative burden across physical, psychological, and social domains of life. Participants described interconnected consequences that extended beyond physical symptoms and collectively reduced QoL. Rather than experiencing isolated symptoms, many described lipoedema as an overwhelming condition that restricted participation, affected relationships, reduced emotional well-being, and generated uncertainty about the future.

Burdened by heaviness

Heaviness had a large impact on daily life. Participants highlighted functional limitations due to constant feelings of heaviness, causing them to feel physical fatigue: “The heaviness and tiredness of the legs, the weight that I feel that I carry all the time, which then impacts on my lifestyle.” P11. Activities like climbing stairs, completing chores, and exercise were noted to be difficult. One stated, “Like leg lowers, for example, most people, that exercise would work for them, but because I had very heavy legs, I wouldn't be able to do it.” P2. Some participants reported that sometimes symptoms of heaviness made it harder to get out of bed.

Far-reaching impacts of pain

Pain was largely communicated by all participants and described as constant aching pains, sharp pains, and sensitivity to pain. Pain not only had impacts on physical function but also was reported to impact relationships and psychological health. Some participants experienced debilitating pain: “it's just the pain like yesterday was so bad. And today that I feel down, I feel like I just want to curl up and not go anywhere.” P4. Most participants mentioned that pain was the most troubling symptom for them and that their QoL would not be as bad if they could eliminate the pain. “I'm always in pain. My legs are always in pain. I'm always in pain. But again, it's what I know. I've lived more in pain than not in pain.” P10.

Relationships were restricted due to pain, and pain sensitivity was also described as a barrier to intimacy: “So even the slightest little touch generally hurts. It's yeah, very painful. So that definitely affects a lot of my life and my partners. Yeah, if he tries to touch me or trying to be sexy. And I'm like, oh, that hurts. Don't touch me.” P6. Participants also described heightened sensitivity and easy bruising, with some reporting significant bruising and discomfort following minor impacts.

Lipoedema causing uncertainty

Many participants discussed concerns in relation to lipoedema and what may happen in the future. Participants were concerned that their lipoedema may get worse or change during pregnancy and/or menopause. They conveyed that their lipoedema is hard to manage now, raising concerns about their ability to manage it in years to come: “how am I going to look after myself” P7. Participants also showed uncertainty in relation to their experiences, “is this normal like why am I finding this heavy? Like do other people's legs feel like this?” P15.

Low mood and emotional distress

Some participants described a large psychological burden attached to living with lipoedema such as depressive feelings, including sadness, hopelessness, and mental fatigue. One participant reflected “And you know what, I have to say now? I'm saying all this stuff out loud. And although I have been living with it for that many years and everything else, it's kind of really depressing.” P3. Some participants also expressed they were irritable and often frustrated with themselves, while also noticing reduced concentration.

Restricted social participation

Participants described restrictions to their social participation due to the physical, psychological, and practical challenges associated with lipoedema. A strong need for control over their environment to manage their lipoedema symptoms and comfort was described by some participants. Many carefully considered the environments in which activities would occur, reporting concerns about prolonged standing, walking distances, seating availability, and physical comfort. One participant stated, “I think it's more of like an anxiety thing of, like, not wanting to go somewhere new because I don't know what the seats will be like or what if I have to stand up the whole time and there's nowhere to sit.” P2. These considerations often restricted the social and leisure activities participants felt able to attend. Some participants avoided activities because they were physically demanding or due to reduced motivation, affecting relationships with others. One participant explained, “when they do things like go on hikes or, you know, it might be a

trip somewhere. It's just too hard." P3. Another said "I get invited places and can't be bothered going, which is really, really bad. It's not me." P4.

Appearance-related concerns frequently resulted in avoidance of social and leisure activities. Some participants describing withdrawing from situations where their legs might be visible, limiting participation in activities such as swimming. One participant explained, "I used to hide away because I didn't want anyone to see my legs or anything else." P3. Another recalled, "I was on a boat and everyone's wearing shorts and jumping into the harbour. And I just thought, well, I'm not doing that because I don't want people to look at my legs. You know, that's how self-conscious you are." P7. These restrictions reflect the broad impact of lipoedema on social engagement and QoL.

Despite these challenges, some participants reported maintaining social engagement when family and friends adapted activities to accommodate their needs. One participant stated, "It's not an issue like they will adapt our outing because I can't walk long distances or I need to sit regularly or things like that. So yeah, very accommodating." P10.

Resistant and fluctuating weight

All participants described difficulties with weight. Regardless of their weight loss efforts, participants reported they struggled to lose weight and even noticed constant fluctuations. "It's exhausting, like seeing your friends. You do the same exercises with them. Go out for walks on the weekends together and they would look fit, and you still look like you don't exercise at all. [...] it seems like what's the point?" P6. Some participants tried hormone-based weight loss injections including Mounjaro and Ozempic, recommended by their GP. They again reported no positive effects reducing weight: "What I did try was Ozempic to lose weight, but it didn't work. I don't know. I must be the only one that it doesn't work for." P12. Most participants expressed that all their efforts to lose weight were disheartening, as nothing seemed to work and increased fear of others believing they were not trying hard enough.

Caught between self-acceptance and social judgement

Participants described a tension between accepting their bodies and anticipating judgement from others. Appearance-related concerns, experiences of weight stigma and difficulties with clothing contributed to negative self-perceptions, reduced confidence and avoidance of social situations. While some participants had begun to accept their appearance, many continued to struggle with how they believed others viewed them. This ongoing conflict between self-acceptance and social judgement had substantial psychological and social impacts, influencing QoL.

Appearance anxiety

Participants expressed worry and concern in relation to their appearance, with most conveying they felt self-conscious about their legs. Most described discomfort in wearing shorts and swimwear, with a heightened anxiety of their legs being visible. They expressed fear of negative judgement from others. One participant expressed, "I was upset about like body image. My perception of what other people thought that I looked like." P8. This internal appearance anxiety was associated with weight stigmatization, one participant described, "I'm scared about people going. Oh, she's just the fat one or, oh, you're too lazy. You obviously don't exercise or don't you know how to stop eating and things like that." P6.

Body dissatisfaction

Most participants had a negative attitude towards their body or its features, with one participant describing their legs as "fat elephant legs" P2. Participants described challenges with their own perceptions of themselves, associated with low self-esteem and confidence in their appearance. One participant explained "you're conscious of your appearance, you're self-conscious about your appearance. And your confidence is affected because you feel that your legs are bigger than others." P9. Most participants expressed persistent

body dissatisfaction, causing them to blame themselves for the way that they look. One participant also reported avoiding looking at herself in a mirror as she found it disheartening.

Challenges associated with clothing

Clothing fit was a common problem. Participants reported feeling restricted when shopping for clothing and described constrained self-expression due to limited availability of comfortable, well-fitting clothing. Boots and shoes for some participants were also reported to be problematic and wearing the incorrect footwear was noted to increase pain. Disproportion was a big factor in clothing fit difficulties, one participant explained “With clothing, I mean it is harder to find something because you know you're smaller on top and bigger on the bottom.” P12. Some participants reported that sometimes they have difficulties being too dressy or were not dressed up enough. One participant described, “I feel like I'm always overdressed [...] if I'm going out with people, they might just wear jeans and a jumper. And it's like, wow, I wish I could wear jeans and a jumper, but I can't. They don't fit me.” P8. Participants expressed that sometimes these clothing struggles get them down, “And there's days where as much as I accepted it [lipoedema] and I am what I am, there's days that I just don't want to get out of bed because I don't know what I'm going to wear.” P10.

Self-acceptance over external validation

Some participants had accepted or have made the attempt to accept themselves despite other's ideals, and public stigma. One participant explained, “I am accepting it a bit more because like I literally cannot change a thing, taking a lot of time and a lot of therapy of not knowing what I had to get to that.” P10. However, many conveyed they were still struggling to accept their appearance. While some participants described working towards self-acceptance, many also remained motivated to pursue changes in appearance, strength, mobility or health. This highlighted the complexity of accepting a body affected by lipoedema while continuing to desire improvement. One participant described this tension, stating, “I'm not going to buy a bigger size because then I'm going to adapt to that size. I've got to try to push myself to get back into my size.” P8.

Weight stigma

Negative perceptions that society attaches to an individual with lipoedema were highlighted by the participants, causing them to feel ashamed. Participants felt that they cannot step outside without feeling judged by others, thinking that they are fat and lazy. “You do get comments, and I've had people come up to me in the shops and advise me about my shopping. You know, I eat a lot of vegetables. I don't like meat and they'll go, oh, that's really good. You must be trying to lose weight. Great job. You'll look good soon. I'm like, this is my normal diet.” P16.

Forced to navigate lipoedema alone

Participants' experiences reflected more than isolated barriers to healthcare. Collectively, delayed diagnosis, limited awareness, dismissive healthcare encounters, and the absence of effective treatment options created a sense of abandonment within the healthcare system. Consequently, participants often felt responsible for recognizing their condition, sourcing information, advocating for their needs, and navigating treatment decisions themselves. This transfer of responsibility from healthcare systems to the individual added a further burden to living with lipoedema and negatively impacted QoL.

Barriers to treatment access and usability

Participants expressed strong frustrations regarding surgical interventions for lipoedema, “Surgery is an option, but it's, you know, ridiculously expensive and not looked at through Medicare.” P6. Cost of compression was also discussed as being a financial burden even if they are supported with well-paying

jobs “it's still a huge dent in my in my pocket” P10. Compression was also seen by most as undesirable, with some participants admitting they do not wear them every day as “it's sort of not really something that goes with my work attire” P6 and “I have to be in the mood to wear them.” P10. Others reported wearing them consistently; however, “It's a lot of effort to put on and off and then when you go to the bathroom.” P15, with some conveying that managing lipoedema is overwhelming and hard to fit into their busy lives.

Delayed diagnosis

Delayed diagnosis was commonly reported. One participant expressed that her delayed diagnosis “makes me feel bad” P2, as for many years they carried self-blame. Another participant identified that they had lipoedema; however, could not receive an official diagnosis “15 years, I was seeking a diagnosis” P14. Another stated “unknowingly I've been suffering with lipoedema for over 20 years” P3. This impacted their ability to take charge of their condition at onset, with no answers to what they were experiencing, resulting in psychological distress.

Health professional dismissal

Most participants described not being believed by health professionals “Its looks like you are lying. They don't trust you” P1, in relation to their eating habits and daily exercise. This caused some participants to reduce intake and develop a poor relationship with food. One participant stated that there were never many treatments recommended “You eat less or you have a gastric band surgery” P2, with others highlighting that their pains were “always just put down to growing pains” P3. This had large impacts on the participant's mental health; one participant expressed, “You know, you feel inadequate about it and at different times I've lost weight. So, I was always a bit confused about it.” P7. Some participants reported that health professionals were still dismissive even with a formal diagnosis “some doctors still say, oh, I don't believe in that.” P6, “That's just a funny way of saying that you're overweight.” P12. This not only created frustration but confusion for participants as they were left to find solutions to their symptoms themselves.

Lack of awareness and recognition

Participants expressed that there was a lack of knowledge of lipoedema by health professionals and the public, “no one knows much about lipoedema. My doctor doesn't know much about it.” P4. They also stated that there is limited information regarding the condition, making “finding someone that understands what lipoedema is very difficult.” P4. Most were frustrated by the lack of government awareness for lipoedema, expressed through “Obesity is recognized with other things, and I don't understand how this isn't. It's not like there's a lot we can do about it. That bothers me a lot.” P6. Some participants expressed that they advocate for themselves “I do try and educate as many people as I possibly can.” P14, where others conveyed, “I haven't been courageous enough to kind of want to educate people about it.” P15. Participants conveyed that they hope awareness will continue to rise similar to conditions such as endometriosis.

Absence of a cure and positive treatments

Participants felt unsupported by the limited effectiveness of available treatment options, contributing to a sense that they were left to manage the condition largely on their own. Participants reported that treatments currently recommended don't work, “I don't see there's any real treatment, successful treatment, which is one of the frustrating things.” P11, causing them to feel helpless and that there is nothing they can do to treat it. This was expressed through using compression stockings “quite frankly, it just does its thing” P13 and “They do help a little bit, but, you know, it just comes back.” P12. Others conveyed that compression pumps cause more pain and did not do anything to relieve their symptoms. No positive outcomes were highlighted by participants who had received manual lymphatic drainage (MLD) “MLD, which I've tried. That didn't do anything.” P12. Participants stated frustrations with exercise “You do all your

weights and all that kind of stuff, but nothing gets rid of it [lipoedema]. It's just always there." P15 and "I have a personal trainer that I go to three times a week and he basically tells me to go on the stair machine a lot, which obviously does nothing for the aesthetic appearance." P9. While some participants expressed concerns "Is there ever going to be a way to cure this" P13, highlighting worry that they will always feel the burden of lipoedema.

Self-directed care and self-recognition

Due to lack of awareness and supportive healthcare, participants showed independence in making health decisions to manage their condition. Many researched lipoedema to gain a deeper understanding as dismissive healthcare left them feeling "You just have to do it yourself." P2. Most participants initially self-diagnosed their lipoedema "I had found a lot of things online that I was very confident that, yeah, that's me." P6. However, some participants felt that social media "shouldn't be how people are getting their health information." P15 and information they found online was "incredibly scary of essentially what was to come for my life." P13, however, they felt they did not have any other option.

Discussion

This study explored the experiences of individuals living with lipoedema to understand the impacts it has on their QoL. Through qualitative methods, four themes were identified: the ongoing work of living with lipoedema, living with a restrictive and overwhelming condition, caught between self-acceptance and social judgement, and forced to navigate lipoedema alone. These themes capture the lives of individuals currently living with lipoedema within Australia, identifying physical, psychological, social, and environmental impacts it has on QoL.

Our study found that individuals with lipoedema felt abandoned by healthcare systems, reporting delayed diagnosis, dismissive healthcare, and limited treatment guidance. Similar findings have been reported in previous qualitative studies, where individuals with lipoedema spent years seeking a diagnosis, visiting several different health providers who were sceptical of their symptoms and were not receptive to their concerns (Christoffersen & Tennfjord, 2023; Dahlberg et al., 2025). As a result, participants in the present study felt responsible for recognizing their condition, advocating for their own care, and sourcing information through online resources such as social media. This transfer of responsibility from healthcare systems to the individual created an additional burden beyond physical symptoms of lipoedema, negatively affecting their QoL. Feelings of abandonment were further reinforced by the individuals' perceptions that currently available treatment options provided limited symptom relief, were difficult to access, or placed considerable financial and practical demands on daily life. Similar healthcare challenges have been reported in women with endometriosis, a chronic condition that also predominantly affects women. Symptoms experienced by those with endometriosis are often dismissed and invalidated, causing them to feel alone in managing their symptoms and are forced to advocate for themselves (De Corte et al., 2025; Fallon et al., 2026). These experiences mirror those reported by individuals with lipoedema in the present study. Increased awareness of endometriosis amongst health professionals and the wider community has been associated with improvements in recognition and diagnosis of the condition over time (Mazza et al., 2025). Similar increases in awareness and recognition of lipoedema could help close these gaps within current healthcare and reduce misdiagnosis of lipoedema. However, continued progress will likely require greater awareness and further development of universally accepted diagnostic criterion (Forner-Cordero et al., 2025).

Participants highlighted that acceptance was often challenging due to ongoing experiences of stigma and concerns about how others perceived their appearance, creating a persistent tension between developing self-acceptance and anticipating social judgement. Weight stigmatization emerged as a significant factor affecting the functioning of an individual with lipoedema, having detrimental effects on their psychological wellbeing. This stigma was derived from health professionals and the public. Consequently, weight stigma caused participants to avoid social activities, reduced their self-confidence, and some were made to blame themselves for the way they looked, despite feeling like they had no control over their appearance. Participants frequently described feeling that their concerns were dismissed or attributed solely to body weight. These experiences may reflect broader patterns of weight bias within healthcare. A

systematic review by Lawrence et al. (2021) found evidence of weight bias among healthcare professionals towards individuals with obesity. These broader patterns of weight bias within healthcare may help explain why participants felt their symptoms and concerns were often attributed to body weight rather than considered in the context of lipoedema.

One of the largest barriers for participants accepting their condition was their dissatisfaction with their body image and appearance. Studies on individuals with chronic conditions have shown that a higher ability to adjusting to life with an illness and its negative psychological impacts is influenced by the ability to accept the illness itself (Bąk et al., 2017; Bień et al., 2020; Rzońca et al., 2018; Szpilewska et al., 2018). Subsequently, a higher acceptance of illness has also been associated with a higher QoL (Jankowska-Polańska et al., 2016). Throughout this study, participants living with lipoedema expressed negative body image concerns and appearance-related anxiety, with most struggling to accept their appearance. A larger BMI in individuals with lipoedema has been associated with a higher burdensome appearance score and a worse perceived QoL (Stellmaker et al., 2026). Similarly, participants in this study reported a lack of self-confidence in relation to their appearance and often modified their clothing choices or avoided social activities, as they were worried about how others perceived them. Participants reported these body image concerns had negative psychological effects, including feelings of depression, anxiety, and low self-esteem. In some participants, they also experienced social isolation as their avoidance of social events had a large negative impact on their relationships with family and friends. These findings highlight the impact that body image concerns can have on the psychological wellbeing, social participation and overall QoL of individuals living with lipoedema.

Throughout this study, participants described lipoedema as having a substantial impact on their QoL that extended beyond physical symptoms alone. The cumulative burden of pain, heaviness, fatigue, and uncertainty influenced daily decision-making, shaped activity choices, and restricted social participation, highlighting physical, psychological, and social impacts of living with lipoedema. These findings are consistent with growing evidence demonstrating significant impairments in individuals living with lipoedema, particularly within the domains of physical functioning, pain, emotional wellbeing, social functioning and fatigue (Günay et al., 2026). In this study, pain and heaviness were often described as the most burdensome symptoms and extended beyond physical discomfort, influencing mood, motivation, and social engagement. Similar findings have been reported previously, with pain identified as a significant contributor to reduced QoL in individuals with lipoedema (Falck et al., 2022; Goodrose-Flores & Björkhem-Bergman, 2026). For many participants, concerns regarding their symptoms and appearance emerged during adolescence, and repeated dismissal of these concerns by health professionals may have contributed to heightened emotional distress and depressive feelings. Participants described experiencing depressive feelings, including sadness and hopelessness related to lipoedema, and heightened irritability often directed towards those around them impacting their relationships. Previous studies have also reported depression and depressive feelings among individuals with lipoedema (Clarke et al., 2023; Falck et al., 2022). However, the relationship between lipoedema and depression is likely complex, and psychological wellbeing may be influenced by multiple factors. Supporting this, a cross-sectional study indicated that individuals with lipoedema reported psychological stress, including depression, a year before their lipoedema-associated symptoms emerged (Erbacher & Bertsch, 2020). These findings suggest that psychological wellbeing in individuals with lipoedema is shaped by a combination of interacting factors, while the ongoing physical, social and emotional challenges associated with the condition can have a substantial impact on QoL.

Participants described living with lipoedema as an ongoing process of adaptation, requiring continual monitoring of symptoms and modification of daily activities to maintain functioning and participation. Individuals regularly adjusted how they completed tasks, balanced activities against symptom exacerbation, and developed strategies to enhance their QoL. This finding is consistent with previous qualitative studies describing lipoedema as a condition that requires constant negotiation between physical limitations and participation in daily life (Christoffersen & Tennfjord, 2023; Czerwińska et al., 2021; Dahlberg et al., 2024; Falck et al., 2025b; Kloosterman et al., 2025; Melander et al., 2022). Participants in our study used conservative management strategies to reducing symptoms of pain and increasing mobility. Compression garments are recommended to reduce the inflammatory process of subcutaneous tissue, helping to decrease pain experienced by individuals with lipoedema (Faerber et al., 2024). Participants in

our study did indicate that compression was beneficial; however, some found them time consuming, hard to fit into their daily life and were uncomfortable to wear in hot environments. Participants within the study reported that they participated in exercise, expressing functional benefits such as increasing balance and strength, while reducing pain symptoms. Exercise participation has also shown to have positive effects on individuals with mental illness, including reducing depressive feelings, negative thoughts and increasing an individual's sense of control (Firth et al., 2016, Firth et al., 2019). Beyond physical self-management strategies, participants also described relief following diagnosis, as it provided validation after years of uncertainty and legitimized many of the self-management strategies they had already adopted. Similarly, support from family members, partners, friends, and colleagues enhanced their ability to adjust to living with lipoedema. This finding is consistent with research demonstrating that support from family members and significant others is an important resource for individuals living with lipoedema and is associated with better health-related QoL (Falck et al., 2025a). A stronger social support from family, friends, and significant others has been associated with better emotional well-being, social functioning, and reduced fatigue in individuals with lipoedema (Falck et al., 2025a). These findings suggest that support networks may play an important role in helping individuals cope with the ongoing demands of managing lipoedema. Living with lipoedema requires substantial ongoing physical and cognitive work, highlighting the invisible effort undertaken to improve functioning, participation, and QoL.

Based on the study findings, several recommendations can be made for further research and clinical practice. Previous literature has highlighted the importance of conservative management for increasing muscle strength and exercise capacity, helping to increase the QoL of individuals with lipoedema (van Esch-Smeenge et al., 2017). Within our study, participants reported an increased mood after exercise. Although participants also experienced frustration at times, as exercise did not show visible improvements in relation to their appearance, they did acknowledge they were stronger and felt better after participating in exercise. Exercise can be performed at little to no cost and should be an important conservative management approach for individuals living with lipoedema, helping to increase physical function and mental wellbeing.

Participants identified negative impacts on their mental wellbeing, which may have been influenced by dismissive healthcare experiences. A study exploring the perceptions, challenges, and needs of lymphoedema healthcare professionals supporting patients with lipoedema highlighted that the ability of health professionals to listen and validate the individual's experiences may reduce the emotional burden of lipoedema and increase support (Cooper et al., 2025). Empathy and compassion are therapeutic tools that should be utilized and could help increase the emotional wellbeing of individuals living with lipoedema (Cooper et al., 2025; Nightingale et al., 2018). Our study identified that participants expressed relief when receiving a diagnosis and when their concerns were finally being heard. This helped reduce the self-blame they had previously experienced due to comments and dismissal by health professionals. Further research should be conducted to identify the relationship between psychological health and empathetic healthcare.

Additionally, positive psychological qualities, such as self-compassion, are linked to an individual's mental wellbeing, helping improve emotional regulation, alter cognitive appraisal, and enhance coping (Baxter & Sirois, 2025). Self-compassion techniques have been identified to reduced body image distress and increased body appreciation in breast cancer survivors (Sherman et al., 2018). In women lower levels of internalized weight stigma and improved psychological wellbeing have also been associated with self-compassion (Fekete et al., 2021). Similarly, recent research emphasizes the potential value of addressing compassion fears for those living with lipoedema to reduce perceptions of shame and self-criticism, helping to support the development of compassion strategies that may have positive impacts on emotional regulation and mental health (Clarke et al., 2026). Individuals living with lipoedema should be equipped with self-compassion strategies, as these tools may help improve QoL while living with lipoedema. Future research should explore interventions that integrate exercise, compassionate healthcare practices, and self-compassion strategies to determine their potential benefits for physical functioning, psychological well-being, and overall QoL in individuals living with lipoedema.

This study does include several limitations. Many participants reported coexisting health conditions. Although these form part of the lived experiences of individuals with lipoedema, it was not possible to establish the extent to which specific QoL impacts were related to lipoedema itself or to other health conditions, as comorbidities were not explored as part of the analysis. The findings should be interpreted with consideration that participants' QoL experiences may reflect the combined impact of lipoedema and

coexisting health conditions. Although online interviews are increasingly recognized as a feasible approach for qualitative data collection, and previous research suggests that online and face-to-face interviews may generate comparable thematic findings, the exclusive use of online methods may have limited participation among individuals with restricted access to technology or lower levels of digital literacy (Guest et al., 2020; Peasgood et al., 2023). Furthermore, data were collected through both individual interviews and focus groups. These approaches may provide different types of data, with focus group discussions encouraging participants to build on shared experiences, while individual interviews may facilitate discussions of more personal or sensitive topics (Bispo Júnior, 2022; Guest et al., 2020). Included participants within this study also received a diagnosis from the same health clinic; therefore, it is not certain if these experiences capture those experienced by the broader population. Additionally, although this study aimed to explore the experiences of individuals living with lipoedema within Australia, most participants were from New South Wales. Therefore, the transferability of these findings to individuals with lipoedema across the broader Australian population may be limited.

Conclusions

Individuals living with lipoedema experience negative impacts on their QoL through physical, psychological and social domains. Findings from this study suggest that reduced QoL is not only influenced by the physical burden of symptoms such as pain and functional limitations, but also by weight stigma and healthcare-related challenges, including delayed diagnosis and dismissive healthcare experiences. Improving awareness and recognition of lipoedema, facilitating access to appropriate management strategies, and acknowledging the psychological impacts of lipoedema may help address current gaps in care and improve QoL in individuals living with lipoedema.

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Author contributions

CRedit: **Rhiannon Stellmaker**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing; **Belinda Thompson**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Supervision, Writing – review & editing; **Vincent Singh Paramanandam**: Conceptualization, Investigation, Methodology, Writing – review & editing; **Kerry A. Sherman**: Conceptualization, Methodology, Writing – review & editing; **Helen Mackie**: Conceptualization, Methodology, Writing – review & editing; **Louise Koelmeyer**: Conceptualization, Investigation, Methodology, Writing – review & editing.

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Notes on contributors

Rhiannon Stellmaker (RS), BExSportSc(Hons), MRes, PhD candidate with the Australian Lymphoedema Education, Research and Treatment Centre (ALERT), School of Health Sciences and Nursing, at Macquarie University, Sydney, Australia. Her thesis focuses on patient-reported outcome measures in individuals with lipoedema.

Belinda Thompson (BT), MCLinExPhys, BEx&SportSc, PhD, is a Course Director/ Senior Lecturer at the Australian Lymphoedema Education Research Treatment Centre (ALERT), School of Health Sciences and Nursing, at Macquarie University, Sydney, Australia.

Vincent Singh Paramanandam (VSP), BPhysio, MPhysio, MSc, PhD, is a Postdoctoral Research Fellow with the Australian Lymphoedema Education, Research and Treatment Centre (ALERT), School of Health Sciences and Nursing, at Macquarie University, Sydney, Australia.

Kerry A. Sherman (KAS), PhD, is a Professor of Health Psychology in the School of Psychological Sciences and a member of the Lifespan Health and Wellbeing Research Centre at Macquarie University, Sydney, Australia.

Helen Mackie (HM), MBBS, FAFRM (RACP), MRes, is a Clinical Associate Professor and Consultant in Rehabilitation Medicine at the Australian Lymphoedema Education, Research and Treatment Centre (ALERT), School of Health Sciences and Nursing, at Macquarie University, Sydney, Australia.

Louise Koelmeyer (LK), BAppSc (OT), PhD, is an Associate Professor and Head of the School of Health Sciences and Nursing at Macquarie University, Sydney, Australia, and is the Director of the Australian Lymphoedema Education, Research and Treatment Centre (ALERT).

ORCID

Rhiannon Stellmaker  <https://orcid.org/0000-0003-1654-0274>

Belinda Thompson  <https://orcid.org/0000-0002-7427-9986>

Vincent Singh Paramanandam  <https://orcid.org/0000-0002-9976-9172>

Kerry A. Sherman  <https://orcid.org/0000-0001-7780-6668>

Helen Mackie  <https://orcid.org/0000-0002-9751-319X>

Louise Koelmeyer  <https://orcid.org/0000-0002-2736-2330>

Data availability statement

The datasets generated and analyzed during this study are not publicly available due to ethical and privacy restrictions, as participants did not provide consent for public data sharing. De-identified data is available from the corresponding author [RS] on reasonable request, subject to appropriate ethics approval.

Declaration of generative AI use

Microsoft 365 Copilot (GPT-5) was used during manuscript preparation to assist with language refinement, copyediting and improvement of writing clarity. Generative AI was not used in the study design, data collection, data analysis, reference selection, interpretation of findings or general conclusions.

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