



Tailored personas for self-management in home-based rehabilitation for participants with lower limb lymphedema: A qualitative study

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ABSTRACT

Background: Lower limb lymphedema is a chronic condition characterized by lymphatic dysfunction and affects a large, increasingly prevalent patient population. While incurable, the condition can be effectively controlled through evidence-based self-management. Current researchers often emphasize universal management principles, overlooking individual variability and multifaceted patient needs, which constrain the efficacy of intervention measures.

Objective: We aimed to develop personas—fictional characters representing distinct patient sub-groups—for self-management among participants with lower limb lymphedema during home-based rehabilitation.

Methods: Purposive sampling coupled with maximum variation sampling was employed to recruit 24 participants with lower limb lymphedema from a vascular surgery center in China. Semi-structured interviews were conducted, and the data were analyzed using qualitative content analysis. The validity and representativeness of the role dimensions were confirmed through expert review and participant feedback, leading to the construction of distinct participant personas.

Results: We identified five distinct personas tailored to participants with lower limb lymphedema. The personas were: proactive and optimistic self-managers; participants with moderate health literacy and fluctuating self-management behaviors; participants with low motivation and emotional disengagement; participants with limited knowledge and constrained self-management behaviors; and participants with high cooperation but excessive health anxiety.

Conclusion: We found substantial heterogeneity in participants' behavioral patterns, which through the developed typology reveals their diverse support needs and provides a framework for developing tailored strategies in future research.

What is already known

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- Self-management is crucial for controlling lower limb lymphedema, a chronic condition.
- Current approaches often overlook individual patient differences, limiting intervention effectiveness.

What this paper adds

- We identified five distinct participant personas, revealing key behavioural patterns in self-management.
- We have provided a framework for developing precision nursing interventions in home-based rehabilitation, should a cause and effect study support the findings.

1. Introduction

Lower limb lymphedema is characterized by swelling of local tissues due impaired lymphatic drainage, leading to the buildup of lymph fluid in the interstitial space (Sleigh and Manna, 2025). Over 200 million people globally are affected by congenital, primary, or secondary lymphedema, and its prevalence continues to increase each year (Torgbenu et al., 2023). Although there is currently no definitive cure for lower limb lymphedema, proper treatment and management can help control disease progression and reduce the risk of complications (Grada and Phillips, 2017). Self-management is essential for alleviating and managing the symptoms of patients with lower limb lymphedema (Hemati and Rivaz, 2024). Complete decongestive therapy is a comprehensive treatment approach for managing lymphedema, typically comprising four components: manual lymphatic drainage, compression therapy, exercise, and skin care (Kasseroller and Brenner, 2023). Currently, it is considered the primary method for effective self-management of lymphedema (Michopoulos, Papathanasiou, Vasilopoulos, Polikandrioti, and Dimakakos, 2020). Additionally, patients may opt for other volume-reduction therapies, including pneumatic compression devices and laser treatments (Abboud et al., 2021). Regardless of the treatment approach, home-based self-management after discharge is widely acknowledged as essential for preventing swelling progression, reducing the risk of infections, and managing related symptoms (Karaca-Mandic et al., 2023).

Current researchers have explored primarily the self-management experiences of patients with lymphedema (Hsu et al., 2024; Yin et al., 2025) and developed scales, consensus guidelines, and intervention programs (Douglass, Mablesen, Martindale, and Kelly-Hope, 2019; Fu, Shen, Zhang, Wang, and Lu, 2024; McLaughlin et al., 2017; Sacks et al., 2024), aiming to establish general principles for self-management. These principles focus on providing patients with the knowledge and skills required to manage their condition. However, in developing general guidelines, individual differences are often overlooked. Such approaches often assume that all patients have the knowledge, motivation, and resources needed to follow the recommendations, neglecting variations in culture, education, economic status, and the diverse needs of patients (Zhu, Chen, Xue, and Zheng, 2022). Role customization involves developing patient prototypes by clustering individuals who share similar characteristics and needs (Galliford, Yin, Blandford, Jung, and Lau, 2022). These roles help capture population heterogeneity by representing distinct subgroups (Yang, Xu, Gao, Zhang, and Wang, 2025). Tailoring self-management strategies to each role allows for more precise patient care and supports individuals in effectively carrying out self-management throughout the rehabilitation process (Coupe, Cotterill, and Peters, 2018). Based on an in-depth understanding of home-based self-management experiences of among patients with lower limb lymphedema, we used qualitative research methods to define tailored self-management roles for participants, offering a foundation for the future design of targeted nursing interventions.

2. Methods

2.1. Study design and participants

A qualitative descriptive design was adopted for this study. Participants were recruited from a vascular surgery center in China between September and November 2024 using purposive sampling combined with a maximum variation approach.

2.1.1. Inclusion and exclusion criteria

Inclusion criteria were as follows: (1) a diagnosis of lower limb lymphedema; (2) engagement in home-based self-management for a minimum of 3 months; (3) aged 18 years or older; (4) ability to communicate in Mandarin and willing to participate; and (5) intact cognitive function with adequate verbal expression skills. Exclusion criteria included: (1) generalized, renal, or cardiac edema; (2) severe comorbid conditions, such as hepatic or renal failure or malignant tumors.

2.2. Data collection

Data were gathered using face-to-face, in-depth, semi-structured interviews. Participants who met the inclusion and exclusion criteria and consented to take part were provided with information about the study's purpose, significance, and confidentiality measures. No material incentives were offered to participants for taking part. Before the interviews, researchers gathered basic sociodemographic information to explore the relationship between participants' self-management behaviors and their social backgrounds.

The interviews were carried out by two researchers, both registered nurses with extensive clinical experience in managing patients

with lower limb lymphedema and trained in qualitative research techniques. Both researchers are female and hold postgraduate degrees. The first author conducted the interviews, while the second researcher handled audio recording and note-taking. The interviewers had no prior relationship with the participants and were not involved in their clinical care at any stage of the study.

The interview setting was selected according to participant preference. Most interviews were conducted in participants' homes, while the remaining sessions took place in quiet teaching rooms at the vascular surgery center. Only the researchers and participants were present during the interviews, which lasted between 30 and 75 min. With participants' permission, all sessions were audio-recorded, and researchers documented non-verbal cues, including tone of voice and body language. The audio recordings were transcribed within 24 h. Data saturation was confirmed following the 22nd interview, after two additional interviews generated no novel information. No participants refused to participate or withdrew from the study.

2.2.1. Interview outline

The research team created a preliminary interview guide informed by an extensive literature review and team discussions. The group discussion involved two physicians, three nurses, and one participant representative. At the start of each interview, researchers clarified to participants that there were no right or wrong answers. They explained that the study aimed to understand participants' authentic experiences and feelings, including any difficulties or challenges, and emphasized that honest responses were essential to the research. The interview guide was further refined through expert consultations and pilot testing with two participants, resulting in the final version: (1) Please describe your experience with self-managing lower limb lymphedema. (2) What thoughts and feelings have you experienced throughout the self-management process? (3) What challenges have you faced in managing your lower limb lymphedema, and how do you usually address them? (4) What type of support or assistance would you like to receive during your self-management journey? (5) What are your hopes or expectations for the future management of your lower limb lymphedema?

2.3. Data analysis

Data were analyzed using content analysis with the assistance of NVivo 12.0 software. The analysis began with the researchers reading all interview transcripts several times to gain a thorough understanding of the data. The analysis was carried out through the following steps: (1) The interview transcripts were reviewed multiple times, and key statements were systematically coded to extract raw data segments representing participants' self-management behaviors. (2) These extracted segments were reviewed to identify patterns and themes that were synthesised into shared characteristics across participants. These common features helped establish the fundamental dimensions for the participant persona labels. (3) Based on relevant literature and the analysis of interview data, three dimensions were established for the participant persona labels: Description, Characteristics, and Needs. (4) Feedback from participants and assessments by experts were used to verify the accuracy and relevance of these dimensions. (5) Using the established dimensions, persona features were identified by integrating the extracted themes with the researchers' clinical experience and knowledge of home-based rehabilitation. Individual participant characteristics were analyzed across these dimensions to develop detailed personas that accurately reflected the participants' behaviors, needs, and contexts. (6) The personas were returned to the participants for verification to ensure they accurately represented their features and experiences. (7) Participants exhibiting similar behaviours or traits were grouped to construct corresponding cohort personas, reflecting the commonalities within the cohort.

This approach to persona development goes beyond traditional thematic analysis by combining individual themes into comprehensive, multidimensional profiles. While thematic analysis highlights recurring patterns, persona synthesis transforms these patterns into representative profiles that capture participants' attitudes, behaviors, and needs, providing a foundation for designing tailored interventions. Two experts were invited to review the entire data analysis process and its results. Each persona was assigned a descriptive label and accompanied by a character illustration to ensure clarity and ease of understanding. These visual representations, together with descriptive text, highlighted the distinctive multidimensional self-management characteristics of each persona.

2.4. Rigour

To reduce social desirability bias, multiple strategies were employed: the interview introduction was carefully structured, neutral probing techniques were applied, and participants were invited to maintain brief diaries before and after the interviews to document genuine experiences and feelings related to their daily self-management. These personal records are typically less affected by social desirability compared with face-to-face interviews (Lavidas, Papadakis, Manesis, Grigoriadou, and Gialamas, 2022).

To maintain methodological rigor, the processes of identifying dimensions and developing personas were reviewed by experts, and the finalized personas were shared with participants for validation. Key decisions were documented in an analytical memo throughout the study to ensure process reliability and establish a transparent audit trail. To enhance the credibility of the findings, a triangulation strategy was employed: (1) Data source triangulation: combining interviews with participant diaries; (2) Investigator triangulation: codes and themes were independently reviewed and discussed by two researchers; and (3) Member checking: preliminary persona descriptions were returned to a subset of participants to confirm their authenticity.

Additionally, the emerging codes, themes, and persona frameworks were regularly discussed in team meetings, which provided a forum for structured peer debriefing by co-investigators with qualitative expertise through critical questioning and alternative interpretations.

2.5. Ethical considerations

The study received ethical approval from the Ethics Committee of China-Japan Union Hospital of Jilin University (Approval No. 2021KYYS007). Ethical approval was obtained before the start of data collection. The study followed ethical guidelines ensuring voluntary participation and the confidentiality of all participants. All participants gave written informed consent and were made aware of their right to withdraw from the study at any time. To protect participants' privacy, all interview data were securely stored, and each participant was assigned an anonymous identification code (P01–P24). All data were used exclusively for research purposes.

3. Findings

The 24 participants comprised 16 women and 8 men, a sex distribution consistent with the higher prevalence of lower limb lymphedema among females (Morfoisse et al., 2021). An overview of participant characteristics is presented in Table 1.

Participant ages ranged from 28 to 75 years, with a mean age of 50 years. The duration of lower limb lymphedema ranged from 0.5 to 20 years, with an average of 6 years. In terms of education, 45.8 % of participants had completed high school or higher. Additionally, 70.8 % of participants were married, and 58.3 % were employed at the time of the study. Five distinct personas were identified to represent patients with lower limb lymphedema, with the detailed characteristics and needs of each persona summarized in Table 2.

Table 1
Overview of the study participants.

Serial Number	Sex	Age	Disease Duration (years)	Educational Level	Socioeconomic Status	Marital Status	Employment Status	Staging of Lymphedema	Major Complications
P01	Female	45	3	High school	Moderate	Married	Part-time	II	Cellulitis
P02	Male	62	8	Junior high school	Low to moderate	Married	Retired	II	Mild fibrosis
P03	Female	28	1	University or higher	Moderate to high	Unmarried	Full-time	II	None
P04	Female	50	5	Junior high school	Low to moderate	Married	Unemployed	II	Moderate fibrosis
P05	Female	70	10	Primary school or below	Low	Married	Retired	III	Elephantiasis
P06	Female	35	2	University or higher	High	Married	Full-time	II	None
P07	Female	58	6	High school	Moderate	Married	Retired	II	Moderate fibrosis
P08	Male	40	0.5	High school	Moderate	Unmarried	Full-time	I	None
P09	Female	52	7	Junior high school	Low to moderate	Married	Unemployed	II	Cellulitis
P10	Female	60	12	Primary school or below	Low	Married	Retired	II	Moderate fibrosis
P11	Male	48	5	Junior high school	Low to moderate	Married	Full-time	II	Cellulitis
P12	Female	30	1.5	University or higher	High	Unmarried	Full-time	II	None
P13	Female	65	15	Primary school or below	Low	Widowed	Unemployed	II	Chronic ulcer
P14	Male	55	9	High school	Moderate	Married	Part-time	II	Moderate fibrosis
P15	Female	42	3	Junior high school	Low to moderate	Married	Part-time	II	None
P16	Female	38	2	University or higher	Moderate to high	Married	Full-time	II	None
P17	Male	75	20	Primary school or below	Low	Widowed	Retired	III	Elephantiasis
P18	Female	47	4	High school	Moderate	Married	Part-time	II	Mild fibrosis
P19	Female	33	0.5	University or higher	High	Unmarried	Full-time	I	None
P20	Male	50	8	Junior high school	Low to moderate	Married	Full-time	II	Moderate fibrosis
P21	Female	29	1	University or higher	Moderate to high	Unmarried	Full-time	II	None
P22	Male	68	18	Primary school or below	Low	Married	Retired	III	Elephantiasis
P23	Male	41	3	High school	Moderate to high	Married	Full-time	II	Mild fibrosis
P24	Female	73	4	Junior high school	Low to moderate	Married	Retired	II	Cellulitis

Table 2
Tailored personas for self-management in home-based rehabilitation for patients with lower limb lymphedema.

Name	Proactive and Optimistic Self-Managers	Patients with Moderate Health Literacy and Fluctuating Self-Management Behaviors	Patients with Low Motivation and Emotional Disengagement	Patients with Limited Knowledge and Constrained Self-Management Behaviors	Patients with High Cooperation but Excessive Health Anxiety
Personas					
Individuals	P03,P08,P12,P19,P21	P01,P06,P14,P16,P23	P02,P05,P17,P20	P04,P10,P11,P22,P24	P07,P09,P13,P15,P18
Age	28-40	35-55	50-75	48-73	42-65
Socioeconomic Status	Moderate or high	Moderate or high	Low to moderate	Low to moderate	Low to moderate
Educational Level	High school or higher	Primary school or higher	Junior high school or lower	Junior high school or lower	High school or lower
Description	The patient demonstrates a positive attitude toward self-management, an optimistic mindset, and is capable of effectively managing the condition.	The patient has a moderate level of health literacy, and their attitude toward disease management as well as self-management behaviors are prone to fluctuate with changes in their health status.	Due to the prolonged and unresolved nature of the condition, the patient lacks motivation for self-management and exhibits emotional numbness.	The patient has limited health knowledge and a generally poor or low socioeconomic status, which restricts their self-management behaviors.	The patient shows a high degree of cooperation in self-management but is excessively tense about disease fluctuations, making them prone to significant anxiety.
Characteristics	<ul style="list-style-type: none"> ●High health literacy ●Positive outlook ●Strong trust in healthcare providers ●Collaborative disease management ●Robust social support 	<ul style="list-style-type: none"> ●Symptom-dependent adherence ●Susceptibility to external factors ●Experience-driven choices 	<ul style="list-style-type: none"> ●Extremely low adherence to self-management ●Limited intrinsic motivation for self-management ●Pessimistic and emotionally detached mindset ●Feelings of inferiority 	<ul style="list-style-type: none"> ●Low educational attainment ●Moderate self-management ability ●Limited financial resources ●Inadequate social support 	<ul style="list-style-type: none"> ●High adherence to disease management ●Strong self-management motivation ●Heightened sensitivity to disease fluctuations ●Significant emotional volatility
Needs	<ul style="list-style-type: none"> ●Specialized disease management guidance. ●Join a lower limb lymphedema peer support group ●Maintain regular communication with healthcare providers 	<ul style="list-style-type: none"> ●Health education and disease-specific knowledge dissemination ●Conduct regular follow-ups to address feedback and answer questions ●Dynamically adjusted disease management plans 	<ul style="list-style-type: none"> ●Personalized disease education ●Behavioral motivation and confidence rebuilding ●Small-goal oriented rehabilitation plans 	<ul style="list-style-type: none"> ●Easy-to-understand health education ●Video and illustrated guides for disease management ●Low-cost medical devices and management approaches ●Multi-dimensional social support system 	<ul style="list-style-type: none"> ●Psychological support and emotion management skills ●A platform for communication with healthcare providers ●Innovative digital tools for tracking lymphedema status

3.1. Theme 1: proactive and optimistic self-managers

Description: This group mainly consists of women aged 28–40 with a disease duration of <2 years. They adopted a positive and proactive approach to managing lower limb lymphedema, strictly following physician-recommended home-based rehabilitation programs, including manual lymphatic drainage and compression therapy. They openly share information about their condition with family and friends and actively seek practical support for daily activities. With a strong awareness of the importance of long-term self-management in controlling disease progression, they are motivated to regularly monitor and report their health status.

Characteristics:

- High health literacy: These patients, typically with higher education levels, have a strong understanding of the pathophysiology of lower limb lymphedema. They follow home-based management principles and practical guidelines closely, implementing self-care measures correctly and consistently.
- Positive outlook: They approach their condition with optimism and effectively incorporate lower limb lymphedema management into their everyday routines.
- Strong trust in healthcare providers: They rely on advice from medical professionals and actively report any changes in their health status.
- Collaborative disease management: They engage family, friends, and healthcare providers as partners to collaboratively plan and discuss strategies for managing their condition.
- Robust social support: They receive consistent support from their social and rehabilitation networks, which reinforces their self-management efforts.

Needs:

These patients have a basic understanding of lower limb lymphedema and seek advanced guidance to deepen their knowledge. They show a strong interest in participating in peer support groups to exchange self-management experiences and receive emotional support. Furthermore, they value regular communication with healthcare professionals to update their status and obtain expert feedback and recommendations.

P03: “I view managing lower limb lymphedema as a long-term process rather than a quick fix. Even though my condition sometimes varies, I strive to remain calm and maintain a consistent daily self-care routine. With the support of my entire family, I feel confident that I can live with this condition peacefully.”

P12: “I feel capable of managing my edema, but occasional fluctuations in my condition make me feel uncertain—an experience that my family and friends often struggle to understand. I hope to connect with other patients who share similar experiences, as it would help me feel less alone in managing this condition.”

P21: “I value receiving professional guidance and clear explanations from the medical team. In my daily life, I take the initiative to learn about my condition, which helps me feel more confident and at ease. I also hope for regular communication with healthcare providers to obtain timely and expert advice.”

3.2. Theme 2: patients with moderate health literacy and fluctuating self-management behaviors

Description: This group generally includes individuals aged 35–55 with varying durations of lower limb lymphedema. They have moderate health literacy, which is reflected in fluctuating self-management behaviors. Their adherence tends to improve when symptoms are severe or following professional guidance but declines when symptoms ease or during busy periods in daily life. While they understand the importance of long-term self-management, their ability to consistently perform self-care remains limited.

Characteristics:

- Moderate health literacy: These patients often have lower levels of education, resulting in a limited understanding of the significance of home-based management for lower limb lymphedema.
- Symptom-dependent adherence: Their motivation and adherence to self-management practices are strongly affected by whether symptoms are present or absent.
- Susceptibility to external factors: Their self-management practices are easily affected by daily stress, emotional changes, environmental shifts, or anxiety about complex procedures.
- Experience-driven choices: Their decisions about self-management are largely guided by how they feel at the moment, rather than medical recommendations, which can lead to underestimating the risks of lower limb lymphedema.

Needs:

These patients require targeted health education to improve their understanding of lower limb lymphedema and emphasize the necessity of long-term management. Strengthening trust and communication with healthcare providers through regular post-discharge follow-ups can reinforce adherence and provide opportunities to address patient feedback and concerns. They also require

management plans that are flexible and can be adjusted according to changes in their condition.

P01: "At the moment, I feel well and can move without difficulty. When I press the affected limb, it does not feel much different from the other one. I understand the risks of lymphedema, as my doctor explained, but I believe that maintaining good hygiene and avoiding injuries is sufficient. Wearing compression garments daily and following a strict exercise routine seems unnecessary, so I only manage my condition when symptoms appear."

P06: "Lately, work has been overwhelming, and, by the time I get home in the evening, I am too exhausted to do anything other than sleep. I currently lack the energy to manage my lymphedema and hope to resume care once my schedule becomes less demanding."

P23: "I recognize that my self-management of lower limb lymphedema is inconsistent because I lack self-discipline. Being alone at home, I sometimes forget or simply feel unmotivated. It would be helpful if the doctors or nurses could check in with me or arrange follow-up appointments, as having someone to keep me accountable would likely improve my consistency."

3.3. Theme 3: patients with low motivation and emotional disengagement

Description: This group mainly includes men aged 50–75 with a disease duration of 8 years or more. During home-based self-management of lower limb lymphedema, they show low motivation and emotional disengagement. Their adherence to prescribed management plans is poor, and they often hold a vague or pessimistic view about the value of long-term self-care, expressing thoughts such as, "It is not going to get better anyway" or "There is no point in doing it." In interactions, they tend to be passive or minimally involved, demonstrating only superficial compliance by following instructions without genuine internal motivation.

Characteristics:

- Extremely low adherence to self-management: These patients often neglect or entirely forgo home-based management practices for lower limb lymphedema.
- Limited intrinsic motivation for self-management: They exhibit minimal initiative to manage their condition, show little interest in improving their health or preventing complications, and often view self-care as pointless.
- Pessimistic and emotionally detached mindset: They tend to be indifferent or pessimistic about their condition and overall health, often accepting their situation with little hope for future improvement.
- Feelings of inferiority: Prolonged experience with lower limb lymphedema and unsatisfactory treatment results contribute to strong feelings of shame. As a result, these patients often hide the affected limb, avoid discussing their condition, and withdraw from social interactions with family and friends.

Needs:

These patients require personalized disease education to enhance their understanding of lower limb lymphedema fundamentals and the rationale behind self-management, emphasizing symptom control rather than curative outcomes. It is essential to provide them with short-term, visible progress feedback. Nurses can help rebuild their confidence in self-management by breaking down the care regimen into manageable, step-by-step tasks. Additionally, the access to a peer-support platform is needed to offer meaningful emotional support.

P05: "During the last follow-up, I listened to the nurse explain a new care method, but I knew I probably would not follow it at home—it always turns out that way. After living with this condition for over 10 years and doing daily rehabilitation exercises without seeing meaningful results, it is hard to stay positive."

P17: "I do not need any support; I do not want to bother anyone. I did not get much schooling, so I struggle to understand medical terms. I live alone and do not have many friends. With this illness, my leg has been swollen for over 10 years—I have just gotten used to it. I suppose this is how my life will be." (The participant then fell silent.)

P20: "When the community held a talk on lower limb lymphedema, I listened to the expert talk about 'perseverance' and 'staying optimistic,' but I just scoffed inwardly—the advice does not match reality. Every time I go out and people stare at my swollen leg, it hurts. Eventually, I just stopped wanting to go out altogether."

3.4. Theme 4: patients with limited knowledge and constrained self-management behaviors

Description: This group mainly includes women aged 48–73 with low educational levels and limited socioeconomic resources. Their capacity to sustain effective long-term self-management of lower limb lymphedema at home is frequently hindered by low health literacy and inadequate self-care skills.

Characteristics:

- Low educational attainment: These patients have limited general knowledge and find it difficult to understand medical terminology, making it challenging for them to follow written instructions or complex verbal guidance.
- Moderate self-management ability: They experience difficulties in independently and correctly implementing their self-management plans.

- Limited financial resources: Their constrained economic circumstances lead them to favor cost-effective management strategies.
- Inadequate social support: They have limited social support, and in some cases, their primary caregivers are unable to offer consistent or appropriate assistance.

Needs:

These patients require easy-to-understand health education on lower limb lymphedema, preferably delivered through visual aids, such as videos or illustrated booklets. Due to financial constraints, they express a strong preference for low-cost medical devices and management strategies to minimize out-of-pocket expenses. Additionally, given their limited social support, establishing a multi-dimensional support system involving family, friends, healthcare providers, and community resources is essential to sustain their self-management efforts.

P04: “Does all this daily management of lower limb lymphedema really make a difference? I have seen people who do not manage it and seem fine. My leg has been swollen for years, and, as long as it does not hurt, I feel like it should be okay.”

P10: “I really struggle to manage these procedures by myself, so I rely on my daughter to help after work. Our family does not have much money, and, with this chronic condition requiring ongoing expenses, there are times I feel like giving up treatment because it is just too costly.”

P24: “I did not have much schooling. During my last follow-up, the nurse explained the homecare instructions, but I could not really understand them. In the end, I just let it go. It would be much easier for me if they provided an illustrated booklet.”

3.5. Theme 5: patients with high cooperation but excessive health anxiety

Description: This group mainly includes women aged 42–65 with relatively high health literacy. During home-based rehabilitation for lower limb lymphedema, they show strong compliance and willingness to cooperate, and are interested in trying new management tools. Although they understand the importance of long-term self-care, they tend to experience excessive anxiety about disease progression or potential complications, often becoming overly sensitive to minor fluctuations in swelling.

Characteristics:

- High adherence to disease management: They follow healthcare providers' home-based management plans for lower limb lymphedema closely, demonstrating strong compliance and effective execution.
- Strong self-management motivation: They are highly committed to self-management, with some patients demonstrating perfectionistic tendencies in their approach.
- Heightened sensitivity to disease fluctuations: They closely monitor changes in the affected limb and often perceive minor variations as indicators of disease progression or potential complications.
- Significant emotional volatility: Their emotions vary according to their perception of the disease. Noticing "abnormal" changes often induces anxiety, whereas professional reassurance or temporary improvement brings relief.

Needs:

These patients require psychological support to build self-confidence and develop emotion-regulation skills for managing anxiety. Given the unsettling nature of lower limb lymphedema fluctuations, they express a strong need for reliable communication channels with healthcare professionals. They also show keen interest in innovative digital tools that can track limb volume changes and provide objective feedback on disease status.”

P07: “I follow my doctor’s recommendations for managing lower limb lymphedema very closely. Whenever I notice a change in the swelling, I contact the doctor immediately. However, this constant vigilance makes me anxious—it feels like my life revolves entirely around it.

P15: “I have had to skip social gatherings and trips with friends because I worry that my condition could suddenly worsen, and changes in environment might raise my risk of infection. As a result, I mostly stay at home. Being able to reach healthcare professionals at any time for guidance would help me feel more secure.”

P18: “I often feel anxious about the unpredictable changes in swelling. If there were a smart device to monitor my condition in real-time, I believe it would help me feel much more reassured.”

4. Discussion

This study explored the variability in self-management behaviors among participants with lower limb lymphedema during home-based rehabilitation and identified five distinct participant personas. The characteristics and needs of each persona were systematically examined to provide a comprehensive understanding of these behavioral differences. We have highlighted substantial variability among participants with lower limb lymphedema, underscoring the need for individualized intervention strategies. Recognizing differences in patient backgrounds, behaviors, and self-management needs allows for the provision of precision nursing, ensuring that support is tailored and genuinely patient-centered (Yang et al., 2025).

We have revealed that proactive and optimistic self-managers showed the most favourable recovery outcomes. These patients are

generally younger and more educated, with strong learning skills and considerable health knowledge. They build trusting relationships with healthcare providers, favour collaborative approaches to disease management, and demonstrate high adherence to medical guidance. Offering comprehensive, professional guidance on disease management can further strengthen their self-management skills (McCourt, Yong, Ramdharry, and Fisher, 2021). However, it is unclear whether their current positive outlook will be maintained over time, considering their relatively short duration of illness (Yaman et al., 2025). Future researchers could use quantitative methods to investigate how disease duration relates to psychological adaptation in patients with lower limb lymphedema. Moreover, we found that even participants with an optimistic outlook included a higher proportion of unmarried individuals, indicating that the challenges associated with lower limb lymphedema may affect decisions related to marriage. This finding aligns with the results reported by Sopamena et al. (Sopamena et al., 2025). Patients in this group, with relatively high health literacy, are better able to obtain, comprehend, and apply health information. However, it also highlights potential health inequities, as not all patients have access to the educational resources necessary to support effective self-management (Burckhardt, 2005). Therefore, in clinical practice, greater emphasis should be placed on establishing a comprehensive support system for patients with limited resources.

We showed that patients with moderate health literacy and fluctuating self-management behaviors often have a limited understanding of the importance of managing lower limb lymphedema. Their adherence to care plans is low, and their self-management practices are highly affected by changes in symptoms and external circumstances. Thus, strengthening trust and communication between patients and healthcare providers is essential (Chichirez and Purcărea, 2018). Well-structured rehabilitation programs can substantially improve patient outcomes (Dyer et al., 2021), highlighting the importance of offering flexible, individualized management plans. The fluctuating behavior of such patients highlights the impact of psychological and emotional factors on chronic disease management. This suggests that interventions for this group should extend beyond knowledge dissemination and incorporate behavioral psychology approaches to address daily life barriers and interfering factors (Arslan, Aydogdu, and Uzun, 2025). At the policy level, future researchers could examine the integration of fundamental lymphedema care into community-based primary healthcare services to establish a more accessible and supportive care environment for patients.

Patients characterized by low motivation and emotional disengagement often experience a long disease trajectory. Over time, this extended course fosters accumulating negative emotions, diminished motivation for self-management, and an increasingly passive approach to their condition. Accordingly, restoring confidence in this group is a pressing priority. Their learned helplessness appears to stem from the cumulative burden of long-term illness, compounded by potential social isolation. Efforts to rebuild confidence should therefore focus on addressing the concrete challenges they encounter in daily life. When designing intervention strategies, educational content should be presented in a clear and accessible manner, while minimizing extensive theoretical discussion to reduce the risk of increasing patient resistance (Hoffmann et al., 2023). At the same time, adopting a small, goal-focused management approach with immediate feedback and reinforcement is recommended to strengthen patients' confidence and improve adherence (Perez and Urcelay, 2025). Patients in this group frequently experience diminished self-esteem as a consequence of their illness. Creating a peer support platform may help foster a more positive mindset and promote psychological adjustment (Yin et al., 2025).

Patients with limited knowledge and constrained self-management behaviors commonly exhibited two key characteristics: low educational levels and limited financial resources. These factors markedly hinder their ability to effectively manage their condition. Therefore, educational materials for this group should be presented visually, broken down into step-by-step instructions, and closely linked to everyday activities (Shen et al., 2025). Simultaneously, a comprehensive support network involving community health workers, family members, and volunteers should be developed to offer both technical guidance and emotional support (Vasconez-Gonzalez et al., 2025). This network not only promotes a sense of care and connectedness but also significantly strengthens patients' self-management abilities (Corrias, Donati, Giorgi, and Tedeschi, 2025). This highlights the need for health policies that prioritize strengthening community healthcare. Patients with lower limb lymphedema often experience substantial financial strain (Koly et al., 2025), which is especially evident in this subgroup, causing them to favour affordable medical devices and cost-effective treatment options. Efforts could be made to create affordable and user-friendly assistive tools for managing lower limb lymphedema, thereby reducing barriers to effective disease management.

We identified a subgroup of patients characterized by high compliance with self-management regimens. However, their high adherence is accompanied by pronounced anxiety regarding their condition, resulting in notable emotional instability. Their heightened sensitivity to symptom changes, along with the inherently variable and lifelong nature of lower limb lymphedema, further increases their psychological stress (Hsu et al., 2024). Researchers have demonstrated that sharing personal feelings can positively affect both disease outcomes and psychological well-being in patients (Sohl, Dietrich, Wallston, and Ridner, 2017) and that psychosocial interventions can significantly influence the progression of chronic conditions (Schneiderman, Ironson, and Siegel, 2005). Thus, offering psychological training in emotion-regulation skills is vital to help these patients maintain a balanced perspective on symptom changes, consistent with the findings of Li et al. (Li, Yan, Luo, and Chen, 2025). Moreover, creating accessible communication channels with healthcare providers for timely consultation is equally important (Guan et al., 2025). Importantly, these patients demonstrate a strong interest in using innovative digital monitoring technologies. On one hand, digital tools can reduce anxiety by offering objective information about their condition; on the other hand, constant self-monitoring may heighten stress. In clinical practice, it is important to help these patients adopt a lifestyle that accommodates their symptoms while enhancing overall quality of life.

Since the study was conducted at a single center, its findings may have limited generalizability to settings with different healthcare systems, cultural norms, or socioeconomic contexts. We recommend that researchers using these findings take into account local healthcare systems, cultural perspectives, and economic conditions, employing the personas as a foundation for evaluation and tailored adaptation. Future studies across multiple sites and varied settings are needed to further validate, refine, and strengthen the findings of this research.

5. Limitations

This study has some limitations. The use of a qualitative design and a single-center sample restricts the generalizability of the identified personas. Additionally, there is a potential for response bias, as participants may have given socially-desirable answers about their self-management behaviors due to the interview context. Moreover, the absence of detailed records of individual rehabilitation plans limits the ability to distinguish the impact of specific interventions from participants' personal behavioral patterns. Consequently, future researchers should focus on longitudinal, multi-center studies with socioculturally diverse participants to validate and further refine these personas. In addition, it is important to explicitly include participants' individual management regimens as a key variable in the analysis.

6. Conclusion

We identified five distinct patient personas, emphasizing the considerable variability in self-management behaviors during home-based rehabilitation for lower limb lymphedema. We have highlighted the need for precision nursing and provided a foundation for future clinical practice and research.

Data availability

Raw qualitative data cannot be shared due to ethical restrictions, anonymized transcripts, interview scheme, and coding decisions are available in the Appendix on reasonable request to the corresponding author.

Ethics approval statement

This study obtained ethical approval from the Ethics Committee of China-Japan Union Hospital of Jilin University (Approval No 2021KYYS007).

CRediT authorship contribution statement

Yucheng Yin: Writing – original draft, Investigation, Data curation. **Lili Zhu:** Software, Investigation. **Yuehan Wang:** Software, Methodology. **Luya Pu:** Visualization, Investigation, Conceptualization. **Jianmei Gong:** Validation, Supervision, Methodology. **Dongmei Han:** Writing – review & editing, Validation, Supervision.

Declaration of competing interest

We declare that we have no known competing interests or personal relationships that could have appeared to influence the work reported in this paper. Yucheng Yin, Lili Zhu, Yuehan Wang, Luya Pu, Jianmei Gong, Dongmei Han.

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