

Experiences of Living with Gynecological Cancer-Related Lymphedema Among Patients: A Systematic Review and Thematic Synthesis of Qualitative Studies

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Purpose: Due to the gap in the existing literature regarding the absence of meta-synthesis of qualitative studies in the field of gynecological cancer-related lymphedema, and the limited attention to patient's experiences, the purpose of this study is to synthesize the qualitative experiences of the subjective real experience of gynecological cancer-related lymphedema patients to provide a reference to formulate clinically targeted strategies for management.

Patients and Methods: Journal articles were identified by conducting electronic searches in PubMed, CINAHL, PsycINFO, Web of Science, Cochrane Library, Embase, Chinese National Knowledge Infrastructure, Sino Med, Wanfang, VIP databases were searched to identify qualitative studies on real patient experiences of gynecological cancer-related lymphedema from inception to February 2026. The Integrating Methods were applied to synthesize and integrate the results. The methodological quality of included studies was assessed using the JBI Critical Appraisal Checklist for Qualitative Research tool. The quality of the synthesis results was assessed using Con Qual.

Results: A total of 12 studies involving 141 patients were included. Three themes and 10 subthemes were synthesized: Three synthesized findings were 1) Impacts of gynecological cancer-related lymphedema on patients, 2) Cognition and adaptation of patients with gynecological cancer-related lymphedema, and 3) Multifaceted support needs of patients with gynecological cancer-related lymphedema. The Con Qual rating of the synthesis results is moderate.

Conclusion: Patients with gynecological cancer-related lymphedema bear dual physical and psychological burdens. Disease cognition and coping strategies exhibit significant heterogeneity across different patients. It is imperative to provide patients with comprehensive support. Future research should broaden geographical coverage and enhance the evidence system to improve the quality of life for patients with gynecological cancer-related lymphedema and to formulate more targeted clinical management strategies.

Keywords: gynecologic malignancies, lower extremity lymphedema, qualitative research, systematic review

Introduction

Globally, gynecological cancers pose a significant threat to women's health. Gynecological cancers accounted for 15.2% of all new cancer cases among women and were the second most common cancer after breast cancer worldwide. In terms of mortality, 680,041 gynecological cancer-related deaths were reported worldwide in 2022, representing 15.8% of all cancer-related deaths among women.¹ In China, approximately 290,000 new cases of gynecologic cancer were diagnosed in 2022, with about 100,000 deaths, which indicates the substantial disease burden.² Oncological surgery with lymphadenectomy is often recommended as the treatment regimen for improving the survival rate of women with gynecological cancer in the early stages.³ Over the past four decades, survival rates of gynecological cancers have increased globally, with notable increases in cervical and endometrial cancers.⁴ While advances in treatment techniques have enabled long-term survival, the complications associated with cancer treatment can affect the quality of life of the patients.⁵

Gynecological cancer-related lymphedema (GCRL) is a prevalent chronic progressive secondary disease that occurs after gynecological cancer surgery. It arises from lymphatic vessel stenosis, occlusion, and fibrosis resulting from treatments associated with malignant tumors. These factors impede lymphatic return in the distal lower extremities, causing a significant accumulation of lymph fluid in the interstitial spaces.⁶ Approximately 20 million patients worldwide suffer from GCRL, with more than 20% of patients undergoing lymph node dissection ultimately developing this condition.⁷ GCRL not only causes physical effects such as pain, stiffness, and limited mobility, but also produces psychological effects such as anxiety and worry, depression and frustration, and loss of self-esteem and femininity. In addition, social effects include the conflicts of women's roles in the workplace, family and society and strained interpersonal relationships. In short, GCRL patients experience an overall decline in quality of life and face challenges in achieving a sense of normalcy and life satisfaction.^{8,9}

There is currently no cure for GCRL. Complete decongestive therapy (CDT) is the criterion standard for treating GCRL,¹⁰ with the therapy involving two phases: the intensive and maintenance phases. The intensive phase is administered by certified lymphedema therapists and involves manual lymphatic drainage, pressure bandaging, resistance exercises, and skin care, with the objective of alleviating symptoms and reducing lower limb volume. In the maintenance phase, patients and/or caregivers play a dominant role in sustaining the gains achieved during the intensive phase. GCRL patients conduct self-management behaviors by continuing the activities from the intensive phase under regular monitoring by nurses or lymphedema therapists. This phase requires patients to make a lifelong commitment to performing these activities.¹¹ Appropriate professional guidance and self-management can maintain or alleviate the degree of GCRL during CDT. Clearly understanding the true experiences and needs of GCRL patients during their illness and treatment process is crucial for improving their treatment adherence and compliance.¹² Currently, numerous domestic and international studies focus on the prevention, treatment and care of GCRL patients. Liao et al¹³ developed a scientific comprehensive nursing intervention plan and conducted application research. However, with the continuous advancement of science and technology, the experiences of GCRL patients in dealing with their diseases are also changing.

Qualitative research offers profound insights into the real feelings and experiences of patients throughout the treatment and rehabilitation phases of illness. However, the subjective nature of such studies and the lack of controllable research conditions highlight the necessity of systematic reviews to integrate relevant findings and enhance evidence reliability. Meta-synthesis serves as a method for collecting, interpreting, comparing, analyzing, and summarizing the results of similar qualitative studies while systematically evaluating qualitative research data. The outcomes of meta-synthesis can provide a deeper understanding of the essence of phenomena and establish a foundation for evidence-based nursing practice.^{14,15} Only an integrative review of studies thus far has included the impacts of female patients living with GCRL. However, this report does not focus on the experiences of GCRL.¹⁶ Therefore, we designed the current study to synthesize evidence from qualitative studies and to summarize and evaluate qualitative research findings related to the real experiences of GCRL patients, and aimed to elucidate the true feelings and inner needs of patients concerning disease treatment, rehabilitation, and life during their illness, ultimately providing healthcare professionals with a basis for formulating targeted intervention strategies.

Materials and Methods

The study utilized a qualitative meta-synthesis approach to systematically analyze existing qualitative research pertinent to the stated research question. This process entailed identifying the research question, conducting a comprehensive literature search, selecting relevant studies, critically appraising their quality, summarizing key findings, and synthesizing the evidence to reveal common themes and insights.¹⁷

This systematic review and meta-synthesis were reported according to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) and the meta-aggregation approach of the Joanna Briggs Institute (JBI).^{18,19} Moreover, this meta-synthesis review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.²⁰ The study was registered in PROSPERO (CRD42025123826).

Search Strategy

We searched registered trial database, such as PROSPERO, before executing search strategy to avoid publication bias that may affect the reliability of the results of this study.²¹ A three-step JBI search strategy was used for the literature search.¹⁹ First, we searched PubMed, CINAHL, and Sino Med to analyze the words in the titles, abstracts, and subject terms. In step 2, we used a combination of medical subject headings (MeSH) and free words to conduct a comprehensive computer search across English- and Chinese-language databases, including PubMed, CINAHL, PsycINFO, Web of Science, Cochrane Library, Embase, Chinese National Knowledge Infrastructure, Sino Med, Wanfang, VIP databases. Afterward, all references from the included studies were screened against the eligibility criteria. In step 3, we searched the reference lists of all included articles for additional research. We also obtained grey literature from Google Scholar. Boolean terms (AND/OR) were used to combine medical subject headings (MeSH) terms and other keywords. Firstly, identified MeSH terms, and then researched papers across different databases, the search terms included *gynecologic cancer, cervical cancer, ovarian cancer, endometrial cancer, lymphedema, lower limb lymphedema, feeling, experience, demand, qualitative research, qualitative study, descriptive phenomenological study, focus group, phenomenology and grounded theory*. The search was limited to research articles published between 2016 and 2026. All references were imported into EndNote 21 to check for duplication and relevancy.

Inclusion and Exclusion Criteria

This study equally emphasizes studies from developed countries and low- and middle-income countries.

Studies were included if they:

- (1) Participants: Studies involved GCRL patients over the age of 18;
- (2) Phenomenon of interest: Patients' experiences, feelings, and perceptions of developing GCRL after gynecologic cancer surgery;
- (3) Context: Hospitals, rehabilitation centers, communities, or at home;
- (4) Study type: Qualitative studies or mixed methods studies that reported qualitative results.

Studies were excluded if:

- (1) Documents that only have abstracts;
- (2) Duplicate publications or incomplete data;
- (3) The full text was not available;
- (4) Non-English or Chinese papers.

If the article did not clearly state the inclusion criteria for patients in the prevention program, the researchers consulted their references or searched their original study to clarify it.

Study Selection

All retrieved articles were imported into EndNote, and duplicates were removed. Two researchers independently screened the titles and abstracts of all articles. Ineligible studies were excluded based on predefined inclusion and exclusion criteria. Full texts of potentially relevant studies were then reviewed independently by both researchers. Discrepancies were resolved through discussion, with a third reviewer consulted when necessary.

Quality Appraisal

The JBI Critical Appraisal Checklist for Qualitative Research (JBI-QARI) was used to assess the quality of included studies. The JBI-QARI includes ten criteria: philosophical perspective, methodology, data collection, data representation and analysis, interpretation of results, researcher reflexivity, ethical approval, and data analysis. Each criterion offers response options of "yes", "no", "unclear", or "not applicable". Quality assessment was conducted independently by two researchers trained in evidence-based nursing, with cross-checking performed. A third-party arbiter resolved disagreements. Studies were reviewed based on the quality assessment results, and none were omitted due to their quality.

Quality appraisal was conducted to critically analyse the quality of existing qualitative studies on patients with gynecological cancer-related lymphedema and to provide guidance for future studies.

Data Extraction and Synthesis

The first author extracted data from the included studies, while the second author reviewed the results. The extracted data contained precise information about the authors, publication year, country, research methods, research subjects, phenomena of interest, research context, and main results. The findings were synthesized using a meta-aggregation approach. The researcher repeatedly read, analyzed, and interpreted the original findings. The original findings were summarized based on the principle of similarity and merged into new categories; in this aggregation, only unequivocal and credible findings were included. By analyzing the links between the categories, we summarized them into final synthesized findings, which were graded according to the Con Qual approach.¹⁹

Results

Characteristics of Included Studies

A total of 470 records were initially identified in electronic databases from inception to February 2026, and 173 were removed due to duplication. According to the eligibility criteria, 297 citations were excluded after preliminary screening. After carefully reading the 24 full-text studies, 13 were excluded, and 12 were included. One of the included studies was from the reference list. The process for selecting included studies is shown in Figure 1. The included studies were published between 2016 and 2025 and involved 3 countries: Australia (n=1), China (n=10), and Japan (n=1). In total, 141 patients were included across all studies. All study characteristic results are detailed in Table 1.

Quality of Included Studies

The JBI-QARI quality assessment report for these 10 studies indicates that 5 to 9 items received a “Yes” rating for each of the 10 questions. However, most studies performed poorly on question 6. In addition, four studies were culturally or

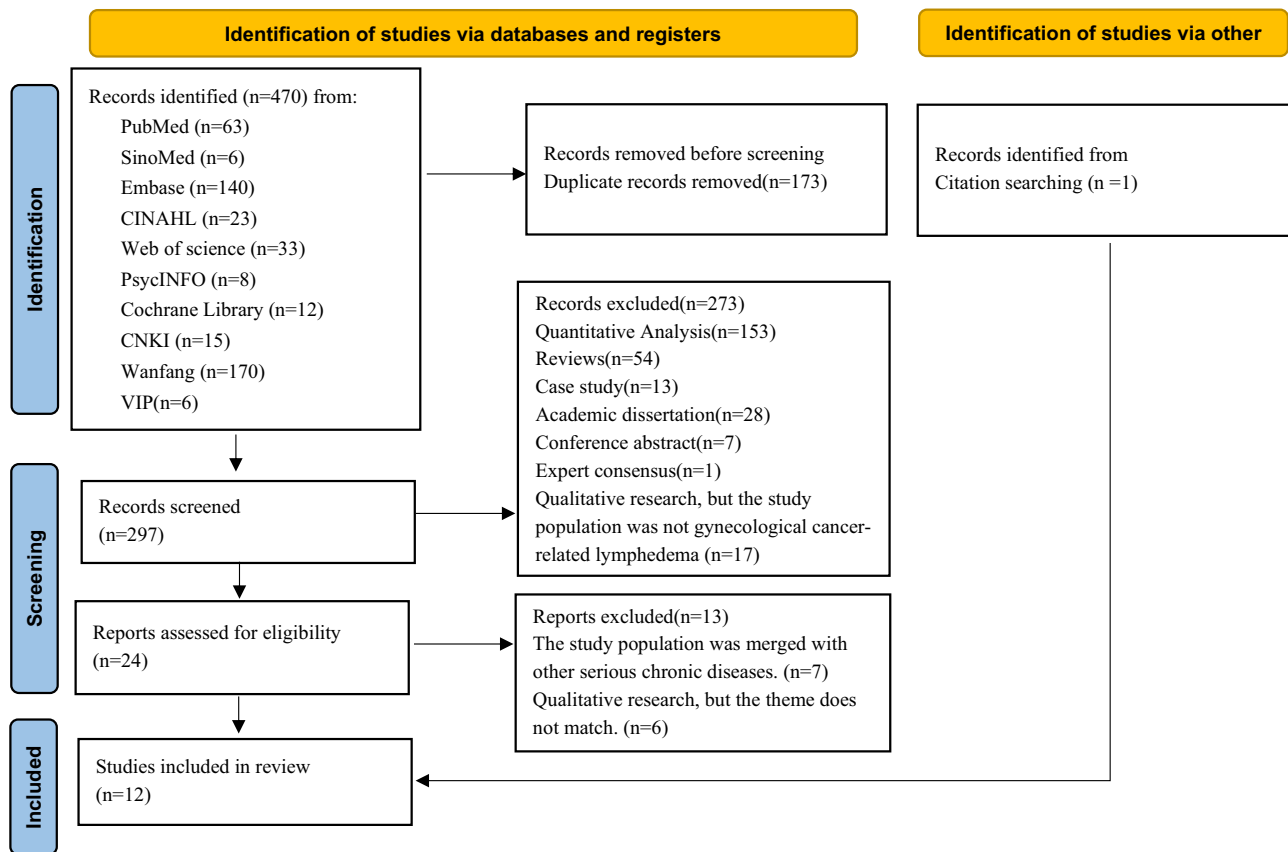


Figure 1 Records identified from citation searching.

Table 1 Specific Information of the Included Studies

Author (Year)	Country	Methodology	Methods for Data Collection	Participants	Phenomenon of Interest	Key Findings
Winch et al ²² (2016)	Australia	Not specified	Semi-structured interview	8 GCRL patients with an average age of 57 years	Sexual concerns of women with GCRL	5 themes: attractiveness and confidence; partner support; functional interruptions; lymphedema coping; sexual role
Zhang et al ²³ (2020)	China	Phenomenology	Semi-structured interview	11 moderate GCRL patients aged ≥18 years	Experiences of patients with moderate GCRL	3 themes: cognitive aspects; attitude aspects; behaviour aspects
Wang et al ²⁴ (2021)	China	Phenomenology	Interview	11 patients with GCRL who received CDT treatment	Authentic experiences of patients with GCRL	3 themes: impact of disease; lack of disease information; hope for life
Jiang et al ²⁵ (2021)	China	Phenomenology	Semi-structured interview	13 stages IA–IIIC GCRL patients aged ≥18 years	Experience of GCRL patients	5 themes: lack of disease-related knowledge; daily life is plagued by illness; emotional cognition modification; lack of family support; the economic burden is heavy
Li et al ²⁶ (2022)	China	Phenomenology	Semi-structured interview	1 51-year-old patients who developed GCRL eight months	Beneficial effects of self-care under a positive mindset on quality of life and physical recovery in patients with GCRL	5 themes: resilient and positive mindset; adhere to professional treatment; think diligently; companionship and support; recommendations for healthcare workers
Luo et al ²⁷ (2023)	China	Phenomenology	Semi-structured interview	16 stage II or higher patients with GCRL who received clinical treatment	Lived experience of home self-management among patients with GCRL	4 themes: lack of self-management skills at home; insufficient support resources; high psychological stress; respond proactively
Seki et al ²⁸ (2023)	Japan	Not specified	Semi-structured interview	13 stage II or higher GCRL patients	Suffering of patients with GCRL	2 themes: suffering of lymphedema developing in lower extremities; supports that allow patients to face the suffering of lymphedema in lower extremities
Yu et al ²⁹ (2024)	China	Phenomenology	Interview	15 patients with GCRL	Compliance with comprehensive lymphoedema management in postoperative GCRL patients	3 themes: cognitive aspects; psychological aspects; family and society aspects
Hsu et al ³⁰ (2024)	China	Describe qualitative study	Semi-structured interview	12 GCRL patients aged ≥20 years	Experiences of GCRL in Taiwanese women	4 themes: lack of awareness and vigilance; suffering from lymphedema symptoms; adaptation to body image changes; self-management in everyday life

(Continued)

Table 1 (Continued).

Author (Year)	Country	Methodology	Methods for Data Collection	Participants	Phenomenon of Interest	Key Findings
Zhang et al ³¹ (2025)	China	Not specified	Semi-structured interview	15 GCRL patients aged ≥60 years	Reasons for delayed medical care among elderly patients with GCRL	4 themes: recognition and assessment of symptoms; health-seeking behavior; obtain a disease diagnosis; face and plan treatment
Liu et al ³² (2025)	China	Phenomenology	Semi-structured interview	16 stage I–III GCRL patients	Self-management experiences at home among GCRL patients	5 themes: inadequate and uneven medical resources for lymphoedema; inadequate support for patients; patients lacking home self-management ability; patients facing great psychological pressure during home Management; home self-management behavior presenting polarization
Tan et al ³³ (2026)	China	Phenomenology	Semi-structured interview	10 GCRL patients managing their lymphedema at home for a minimum duration of 1 months	Lived experiences of Chinese women with GCRL	4 themes: the burden of illness and psychological adaptation struggles; the knowledge-practice gap in self-care; limitations in social and systemic support networks; the critical demand for professional nursing support.

Abbreviation: CDT, complete decongestion therapy.

theoretically positioned and seven addressed the influence of the researcher and participants and described the methods and strategies adopted by researchers in quality control. All quality appraisal results are detailed in [Table 2](#).

Themes and Sub-Themes

Three overarching meta-themes emerged from the review synthesis: 1) Impacts of gynecological cancer-related lymphedema on patients, 2) Cognition and adaptation of patients with gynecological cancer-related lymphedema, and 3) Multifaceted support needs of patients with gynecological cancer-related lymphedema.

Theme 1 Impacts of Gynecological Cancer-Related Lymphedema on Patients

Sub-Theme 1 Patient's Daily Life and Social Activities are Limited

Following gynecological cancer surgery, patients with GCRL may experience symptoms such as limb swelling, heaviness, numbness, and weakness. These symptoms exacerbate their disease-related distress and intensify negative experiences. Patients often struggle with self-image issues, expressing concerns such as,

I always pay close attention to my legs and don't want others to see them. I'm afraid that if they see my legs, they will feel uncomfortable.²⁷

Pain and limited joint mobility compel patients to actively avoid sexual intercourse, with one stating,

If we talk about sexual life, body position will be greatly affected because some movements are just impossible and the legs can't move at all.²²

Additionally, some patients experience sleep disturbances, frequently having difficulty falling asleep or waking up during the night, which significantly impacts sleep quality. One patient noted,

Table 2 Quality Appraisal of Studies Using JBI-QARI Instrument

Study Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Quality Level
Winche et al ²²	Y	U	U	U	Y	Y	Y	Y	Y	Y	B
Zhang et al ²³	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
Wang et al ²⁴	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
Jiang et al ²⁵	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
Li et al ²⁶	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
Luo et al ²⁷	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
Seki et al ²⁸	Y	Y	Y	Y	Y	N	N	Y	Y	Y	B
Yu et al ²⁹	Y	Y	Y	Y	Y	N	N	Y	Y	Y	B
Hsu et al ³⁰	Y	N	Y	Y	Y	Y	N	Y	Y	Y	B
Zhang et al ³¹	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	B
Liu et al ³²	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	B
Tan et al ³³	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	B

Notes: Q1, Is there congruity between the stated philosophical perspective and the research methodology? Q2, Is there congruity between the research methodology and the re-search question or objectives? Q3, Is there congruity between the research methodology and the methods used to collect data? Q4, Is there congruity between the research methodology and the representation and analysis of data? Q5, Is there congruity between the research methodology and the interpretation of the results? Q6, Is there identifying the researcher culturally or theoretically? Q7, Is there influence of the researcher on the research? Q8, Are participants, and their voices, adequately represented? Q9, Is there ethical approval by an appropriate body? Q10, Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Abbreviations: Y, yes; N, no; NA, not applicable; U, unclear. B, the study partially meets the above standards.

I feel my legs are very heavy, as if there is a bucket hanging on them. It's very uncomfortable whether I'm sitting, standing, or lying down.²⁵

Furthermore, they may develop cellulitis, as indicated by a patient who remarked,

Due to repeated cellulitis, my legs have been getting thicker.²⁸

CDT is a widely utilized conservative treatment for GCRL, including manual lymphatic drainage, pressure therapy, functional exercise, and skin care.¹⁰ Patients have reported that manual lymphatic drainage is time-consuming and cumbersome,

Sometimes the machine temperature can become too high. This will cause me pain and my legs will swell again.³⁰

During compression therapy, patients often experience discomfort and restricted mobility. One patient admitted:

I don't wear pressure stockings every day. I find it inconvenient to wear them. When my legs are swollen and uncomfortable, I just put them on.²⁷

The therapy requires long-term adherence to maintain efficacy, which often makes it difficult for patients to integrate into daily. This challenge can result in "role conflicts", as one participant stated:

As a housewife, I feel it is my responsibility to take care of the family. It was tough for me when I realized that I had to bear everything alone.²⁸

Sub-Theme 2 Patient's Emotional Changes During Adaptation to the Disease

The patient experienced negative emotions due to self-image impairment and physical functional limitations caused by GCRL,

My legs have been swollen for 8 years. Both legs are swollen, and it has never been cured. Now I'm just afraid that the swelling will get even worse. I often sigh involuntarily and feel very sad for no reason. I don't understand why all these bad things have happened to me. It's so helpless...²⁵

This state may lead patients to adopt a self-denying attitude toward the impact of lymphedema on their sexual life, as one patient stated:

I feel particularly useless. I would also ask myself if it was my own problem. But I just feel that I haven't done my best.

Some patients adopt an avoidance attitude due to fear or concern about the impact on family life,²² candidly admitting:

I don't want to come to the hospital anymore after chemotherapy. I feel it's very painful to see a doctor.³¹

They worry that physical activities will worsen leg swelling, as one patient noted,

After physical activity, I can clearly feel that my legs have become heavier.²⁸

Furthermore, feelings of despair have emerged, with one patient recounting,

I went to the local traditional Chinese medicine hospital to ask, and later the doctor gave me acupuncture, but it was of no use. I think it will never be cured.²³

Some patients acknowledge the significant benefits of manual lymphatic drainage, stating,

Massaging from a professional therapist has become the greatest pleasure for me when I feel life is worth living.²⁸

They are willing to coexist with GCRL throughout their illness, as one patient noted,

Since the doctor said my illness could be improved through treatment and self-management, I believe I can definitely overcome it.²⁷

Another patient confronts their present reality with positivity:

Through reading books and receiving massages at the clinic, I have come to deeply understand that 'this is just a disease too'; that is why I can now discuss lymphedema with those around me.²⁸

Sub-Theme 3 The Patient's Family Members are Experiencing Increased Burdens of Living

Patients reported that GCRL not only causes significant disruption in their personal lives but also impacts family members. In many regions of our country, CDT treatment is not covered by medical insurance, placing an even heavier financial burden on patients with limited means. ("My son sold the house to treat my illness. My daughter-in-law thought the family was poor. I don't want to burden my son anymore".²⁵ Due to the challenges posed by distance, patients often depend on their families for support. ("I usually live alone. Even though I have only one son, he is very busy. It's not easy for him to travel to Shanghai. It's hard to see a doctor in Shanghai. If it's just for this little thing, I'll go to see a doctor. What if I'm hospitalized again?").²³

Theme 2 Cognition and Adaptation of Patients with Gynecological Cancer-Related Lymphedema

Sub-Theme 1 The Patient's Understanding of GCRL and Their Disease Management Level are Limited

The patient lacked awareness of GCRL.

My legs haven't swollen yet after a month of radiotherapy. It's only this month that they have swollen. I had no idea that GCRL would happen again, and no one ever told me about it.²⁴

Patients focused more on cancer treatment and the recurrence risks than on complications.

Initially, my leg was only slightly swollen; I thought it would improve with time, but it progressively worsened. After consulting the surgeon who previously operated on me, I learned that it was lymphedema.²⁵

There exists a cognitive misunderstanding regarding the condition.

My neighbor mentioned that she frequently experiences swollen legs. She suspects this may result from prolonged sitting or a sudden increase in the frequency of leg exercises. She believes that applying hot compresses at home, taking more frequent foot baths, and reducing her walking will alleviate the condition, thus eliminating the need for a hospital visit for a check-up.²⁹

Furthermore, patients lack professional care methods for the affected limb, including protection, observation, and management measures.

My daughter advised that elevating my feet slightly while sleeping could reduce swelling. I tried it, and it was indeed effective.³¹

Sub-Theme 2 The Patient Values and Actively Responds to GCRL

When patients gradually come to understand that GCRL is a lifelong chronic condition, they progressively overcome barriers, proactively seek disease management strategies, and take control of their daily lives to manage symptoms and prevent lymphedema from worsening. Throughout the treatment process, the patient described their self-management, stating,

The doctor told me not to touch it, not to rub it, just to gradually lift myself up.²⁴

Put self-acceptance first and do not lose the recognition of self-worth due to the occurrence of lymphedema.

It's about facing yourself, remembering who you are, and knowing that you are the most important person in your life.²²

The patient also harbors a strong desire for the disease to revert to a normal state, expressing a willingness to endure any cost in the pursuit of a cure:

I hope to be treated and recover well. Even so, I have this disease (lymphedema), and I still hope to be happy and live a long life.²⁴

Proactive measures should be taken to prevent lymphedema from worsening, including closely monitoring symptoms and adjustment diet. For instance, closely observing lymphedema and modifying dietary habits.

This practice allows for the identification of potential dietary triggers; if leg swelling occurs the following day, the same food can be consumed again to confirm its role in the swelling.³⁰

There was significant interest in innovative and accessible models of care delivery. As one participant articulated,

If AI-powered tools could monitor my limb circumference and guide treatment remotely, elderly patients like me could receive professional support without leaving home—that would be ideal.³³

Sub-Theme 3 The Patient's Social Confidence Has Significantly Increased

As legs swelling subsided, some patients experienced reduced feelings of shame, which in turn boosted their social confidence. One patient shared,

When I was just discharged from the hospital and went home, I forgot how to do manual lymphatic drainage. So I asked the therapist in the WeChat group and kept watching videos. Now I have learned it all, and sometimes I even teach other patients how to do it.²⁷

Theme 3 Multifaceted Support Needs of Patients with Gynecological Cancer-Related Lymphedema

Sub-Theme 1 Medical Resource Support

During GCRL, patients express a strong desire for information about lymphedema from healthcare professionals to better understand their symptoms and management strategies. One patient noted,

After cancer surgery, the notification from healthcare professionals about lower extremity lymphedema and its care is insufficient. The nurse only taught me what exercises I should do after being discharged from the hospital, such as raising

my toes and performing leg massages, but did not explain the knowledge related to lymphedema. Consequently, I knew nothing about lymphedema. It was not until I developed cellulitis that I realized it was caused by lymphedema.³⁰

Furthermore, patients reported that some healthcare professionals lack knowledge regarding GCRL disease management, which may lead to worsening conditions. As one patient remarked,

Some patients believe in dietary remedies or do not eat at all, which indicates that there are gaps in the nutritional treatment and education of cancer patients by medical staff.²⁶

Primary hospitals in remote and economically disadvantaged areas face significant shortages of medical resources. These facilities often lack specialized lymphoedema units and trained medical personnel. Additionally, essential supplies for lymphoedema treatment, including stockinette, gauze bandages, padding materials, and low-stretch bandages, are frequently unavailable.

There's no lymphedema service at the nearby community health center. Going to the hospital is exhausting for us.³³

Sub-Theme 2 Family Support

Patients require social support and encouragement from family, friends, and fellow patients to cultivate the courage and motivation needed to overcome their illness, thereby improving their prognosis. One patient emphasized the critical role of familial support, describing it as a vital force for perseverance:

My husband is very concerned. He always checks on his phone to see if he can get better by eating and such. He is very concerned.²⁴

Sub-Theme 3 Peer Support

By seeking peer support, patients enhanced their self-management skills and advanced lymphedema recovery:

When I feel troubled and want to give up, I complain to other patients. They often encouraged me and demonstrated the effects of their treatments, which gave me confidence.²⁷

Additionally, the patient received understanding from colleagues:

When conducting fire drills and the like, I said I couldn't participate. They all understood and took the initiative to say, 'All right then. You just need to make the call.'²⁸

Sub-Theme 4 Financial Support

For certain patients, the financial burden of outpatient or inpatient treatment does not significantly impact their lifestyle. One patient noted,

Here I can use medical insurance, and it's also closer, so I can come here once a week.²⁸

Another patient noted,

Cancer treatment has been costly, and the expenses for oedema treatment and compression socks are not affordable. Unfortunately, health insurance does not cover it, making it quite burdensome.³²

Confidence Grading of the Synthesized Findings

This study summarizes three integrated findings based on comprehensive research. All include studies, and the evidence grading results are shown in [Table 3](#). Dependability downgrading occurred in the 3 synthesized findings because of methodological quality issues. Of the 12 included studies, most provided no statement on locating the researcher and no acknowledgment of researcher influence on the research. In the 5 questions of the JBI Critical Appraisal Checklist tool (C2, C3, C4, C6, and C7), there were 2 to 4 responses with "yes" for the citations of each synthesized finding. Therefore,

Table 3 Con Qual Summary of Findings

Synthesized Findings	Dependability	Credibility	Con Qual Level	Citations
1. Impacts of gynecological cancer-related lymphedema on patients	Downgrade one level	Remains unchanged	Moderate	[22,23,25,27,28,30,31]
2. Cognition and adaptation of patients with gynecological cancer-related lymphedema	Downgrade one level	Remains unchanged	Moderate	[22,24,25,27,29–31,33]
3. Multifaceted support needs of patients with gynecological cancer-related lymphedema	Downgrade one level	Remains unchanged	Moderate	[24,26–28,30,32,33]

the dependability of each synthesized finding was downgraded by 1 level based on the grading approach. Credibility downgrading occurred when not all the findings included in a synthesized finding were considered unequivocal. We ascertained that synthesized findings 1, 2, and 3 were unequivocal and therefore remained at “no change”. According to the criterion of confidence grading, the overall Con Qual score for synthesized findings 1, 2, and 3 was at a moderate level.

Discussion

Patients undergoing gynecologic cancer surgery frequently develop postoperative lymphedema (GCRL), which is associated with surgical intervention, tumor-induced lymphatic obstruction, radiation therapy, and infection.⁷ Research indicates that lymphedema significantly impacts patients’ daily activities and social engagements, leading to body image disturbances, activity limitations, reduced independence, and feelings of shame and inferiority. The management of GCRL is protracted and intricate, potentially causing patients to feel overwhelmed by the lifelong treatment regimen. Previous studies have confirmed a reciprocal association between mental health disorders and chronic illnesses.³⁴

However, patients with higher psychological resilience can confront and accept the reality of lymphedema calmly, effectively managing their condition through mental adjustment.³⁵ It was found that GCRL patients experience a diminished quality of life compared to those with breast cancer-related lymphedema (BCRL). This may stem from greater lower-limb compared to the upper limbs. Additionally, the further increase in venous pressure during walking exacerbates discomfort, ultimately leading to heightened functional limitation and symptom severity. Consequently, GCRL patients urgently require immediate support from healthcare professionals, family members, and fellow patients. Psychosocial support can enhance patients’ self-efficacy and promote health-related behaviors.²⁵ Healthcare professionals should encourage patients to maintain open communication with family members, actively express emotions, and collaboratively participate in disease management. Additionally, healthcare professionals should facilitate peer connections, enabling individuals with greater psychological resilience to offer emotional and informational support to those who may respond negatively, whether through face-to-face interactions, phone calls, or online communication. This approach not only strengthens patients’ confidence and capacity to cope with the disease but also alleviates their suffering.³⁶

The integrated findings reveal limitations in patients’ understanding of lymphedema and disease management. Research indicates that GCRL patients exhibit a lower awareness of lymphedema compared to BCRL patients.³⁴ All participants in this study expressed a need for specialized guidance from healthcare providers. Research has identified gaps in healthcare professionals’ knowledge regarding disease-related diagnosis, treatment, and care, including insufficient understanding of patient conditions and interdepartmental buck-passing.³⁰ These factors exacerbate patients’ perceptions of disease onset or progression.³⁷ To enhance patients’ awareness of lymphedema and provide effective professional guidance, the primary step is to elevate the awareness and expertise of medical staff concerning the knowledge and management skills associated with lymphedema. This will ensure patients undergoing surgery for gynecological cancers receive timely health education from professionals, increasing attention to the condition and ultimately reducing the risk of lymphedema. In the future, enhancing the management capacity of lymphedema

patients could involve applying empowerment theory by healthcare professionals. This approach should consider both self-empowerment and external empowerment.³⁸ Patients should be encouraged to express their perspectives on the condition and collaboratively establish rehabilitation objectives with healthcare professionals. This process fosters active patients' involvement in disease management. Additionally, healthcare institutions will train additional specialized nurses to treat lymphedema. Discharged patients may choose online lymphedema nursing clinics or receive door-to-door offline service to assist in disease management, thereby improving the level of care provided to patients and their families.

Previous studies have demonstrated that CDT can significantly enhance lower limb functional activity and improve the quality of life for patients.³⁹ While CDT is considered the gold standard treatment for GCRL and effectively manage symptoms, the conflict between its therapeutic attributes and the daily life requirements of patients poses a significant barrier to treatment adherence.⁴⁰ Research identifies key challenges associated with CDT primarily involve: 1) The significant time investment required for CDT, encompassing manual lymphatic drainage that competes with patients' daily tasks and social engagements; 2) Issues such as sweating, rashes from compression stockings in hot weather, and discomfort from machine heat, highlighting inadequate consideration of individual skin variations in compression stocking design; 3) Limitations on travel while undergoing CDT treatment, constraining patients' social engagement space; 4) The patient has incurred significant medical costs throughout cancer treatment, aligning with the findings of Yin et al⁴¹ However, the onset of GCRL may impede the patient, potentially disrupt their employment or leading to work disability. Lymphedema treatment is prolonged and costly, imposing a substantial financial strain on the family and contributing to treatment delay, aligning with Li et al's findings on upper limb lymphedema patients.⁴² In conclusion, it is recommended to establish a three-tiered support network integrating family, community, and hospital resources. This collaborative framework can systematically address issues such as educational gaps, resource fragmentation, and discontinuities in follow-up care. Future research should evaluate the cost-effectiveness of this model across various healthcare systems. Concurrently, healthcare professionals must continuously assess patients' conditions throughout the treatment process, develop a personalized "Pyramid Model" for lymphedema care, validate the proposed conceptual framework in larger and more diverse populations, and explore the integration of emerging technologies, including artificial intelligence and telehealth, into lymphedema management. These initiatives may facilitate a transition from reactive treatment to proactive prevention, ultimately enhancing care quality and patient well-being.^{33,43}

Limitations

This study identifies several limitations that must be considered when interpreting its findings. The quality of evidence supporting the three overarching conclusions was assessed using the conquest method. Among the 12 studies analyzed, 10 were conducted in China. The limited representativeness of non-Chinese research necessitates acknowledgment of the potential geographical bias that may influence generalizations. Consequently, caution is advised when extrapolating these results to other regions. The included studies were conducted across a variety of domestic and international healthcare systems at varying levels of socio-economic development. These systems vary in terms of the availability, accessibility, and development of healthcare services, such as health insurance coverage. Furthermore, the cultural contexts of different countries may shape the healthcare experiences of GCRL patients, influencing their understanding of GCRL, the burden of family caregiving, and the role of women within the family. These potential variations underscore the complexity of healthcare experiences for patients both domestically and internationally, which may further constrain the generalizability of the study's summary results.

The study period of the included research spanned from 2016 to 2026. Most studies in the review scored "No" or "Unclear" on item 6 of the JBI-QARI, which prompts us to reflect on the common lack of reflexive reporting in qualitative research may reduce the reliability and credibility of qualitative research meta-integration results. Recent studies are more aligned with current policies and public awareness improvements regarding GCRL. With an increasing number of qualitative studies, researchers are refining reporting standards based on previous practices to enhance quality. Consequently, recent studies demonstrate improved methodological rigor, strengthening the relevance and reliability of the evidence. The impact of temporal factors on result consistency assessment should be taken into account. Future research

should broaden the geographical scope and enhance the evidence framework to establish an evidence-based foundation for enhancing the quality of life for GCRL patients in clinical settings and devising more tailored intervention strategies.

Conclusion

This meta-synthesis elucidates three primary real-life experiences among GCRL patients: the impact of GCRL on daily life and social interactions, emotional fluctuations during disease adaptation, and the heightened financial burden on family members. Patients' cognitive processes and adaptation statuses to GCRL include limited cognition and disease management capabilities, a notable increase in attention and proactive responses to GCRL, and enhanced social confidence. Patients urgently require comprehensive support system encompassing medical resources, family and friend assistance, and peer support. The integrated assessment indicates moderate integration levels. Based on these findings, this study proposes three targeted intervention strategies: firstly, establishing a tailored psychosocial support network to strengthen family and peer support systems and boost patients' resilience in coping with the disease. Secondly, enhancing the training of healthcare professionals in knowledge and skills related to GCRL and patients' disease management capabilities through the application of empowerment theory. Thirdly, it is essential to optimize the CDT plan by advocating for the inclusion of treatment items in medical insurance, standardizing the prices of treatment supplies, and developing personalized treatment plans to overcome barriers to treatment adherence.

Acknowledgments

Thank you to all the authors and participants of the original research paper, it was their research that made this study possible.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This study was supported by the Joint Fund Program of the Science and Technology Department of Liaoning Province (Grant No. 2023-BSBA-223); the High-Level Talent Launch Fund Project Program of Liaoning University of Traditional Chinese Medicine.

Disclosure

The authors report no conflicts of interest in this work.

References

1. Bray F, Laversanne M, Sung H, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin.* 2024;74(3):229–263. doi:10.3322/caac.21834
2. Han B, Zheng R, Zeng H, et al. Cancer incidence and mortality in China, 2022. *J Natl Cancer Cent.* 2024;4(1):47–53. doi:10.1016/j.jncc.2024.01.006
3. Koh WJ, Abu-Rustum NR, Bean S, et al. Cervical cancer, version 3.2019, NCCN clinical practice guidelines in oncology. *J Natl Compr Canc Netw.* 2019;17(1):64–84. doi:10.6004/jnccn.2019.0001
4. Zhou XH, Yang DN, Zou YX, et al. Long-term survival trend of gynecological cancer: a systematic review of population-based cancer registration data. *Biomed Environ Sci.* 2024;37(8):897–921. doi:10.3967/bes2024.133
5. Carlson JW, Kauderer J, Hutson A, et al. GOG 244-The lymphedema and gynecologic cancer (LEG) study: incidence and risk factors in newly diagnosed patients. *Gynecol Oncol.* 2020;156(2):467–474. doi:10.1016/j.ygyno.2019.10.009
6. Xia L, Cui C, Nicoli F, et al. Far infrared radiation therapy for gynecological cancer-related lymphedema is an effective and oncologically safe treatment: a randomized-controlled trial. *Lymphat Res Biol.* 2022;20(2):164–174. doi:10.1089/lrb.2019.0061
7. Dessources K, Aviki E, Leitao MM. Lower extremity lymphedema in patients with gynecologic malignancies. *Int J Gynecol Cancer.* 2020;30(2):252–260. doi:10.1136/ijgc-2019-001032
8. Manrique OJ, Bustos SS, Ciudad P, et al. Overview of lymphedema for physicians and other clinicians: a review of fundamental concepts. *Mayo Clin Proc.* 2022;97(10):1920–1935. doi:10.1016/j.mayocp.2020.01.006

9. Hsu YY, Nguyen TT, Chou YJ, Ho CL. Effects of exercise on lower limb lymphedema in gynecologic cancer: a systematic review and meta-analysis. *Eur J Oncol Nurs*. 2024;70:102550. doi:10.1016/j.ejon.2024.102550
10. Executive Committee of the International Society of L. The diagnosis and treatment of peripheral lymphedema: 2023 consensus document of the international society of lymphology. *Lymphology*. 2023;56(4):133–151.
11. Zeng Y, Liu G, Peng Z, Hu J, Zhang A. Application of complete decongestive therapy in patients with secondary bilateral lower limb lymphedema after comprehensive treatment of gynecological malignant tumor. *Lymphat Res Biol*. 2024;22(1):60–65. doi:10.1089/lrb.2023.0029
12. McNeely ML, Al Onazi MM, Bond M, et al. Essential components of the maintenance phase of complex decongestive therapy. *Med Oncol*. 2024;41(11):289. doi:10.1007/s12032-024-02442-1
13. Liao X, Cao G, Yang L, Wang C, Tian C. Postoperative effectiveness of comprehensive nursing intervention for lymphedema in gynecological cancer: a controlled study. *Altern Ther Health Med*. 2023;29(6):242–247.
14. Lachal J, Revah-Levy A, Orri M, Moro MR. Metasynthesis: an original method to synthesize qualitative literature in psychiatry. *Front Psychiatry*. 2017;8:269. doi:10.3389/fpsy.2017.00269
15. Zuo HX, Ke YF, Niu YM, Li Y. The method and significance of meta-synthesis. *Int J Nurs Sci*. 2017;36(21):2887–2891,2927. doi:10.3760/ema.j.issn.1673-4351.2017.21.003
16. Dehn P, Rasmussen A, Seiback L, Sekse RJT, Thimm AM, Olesen ML. Impact of lymphedema on women's lives after gynaecological cancer: an integrative review. *Scand J Caring Sci*. 2026;40(1):e70189. doi:10.1111/scs.70189
17. Shaheen N, Shaheen A, Ramadan A, et al. Appraising systematic reviews: a comprehensive guide to ensuring validity and reliability. *Front Res Metr Anal*. 2023;8:1268045. doi:10.3389/frma.2023.1268045
18. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol*. 2012;12(1):181. doi:10.1186/1471-2288-12-181
19. Aromataris E. Furthering the science of evidence synthesis with a mix of methods. *JBI Evid Synth*. 2020;18(10):2106–2107. doi:10.1112/JBIES-20-00369
20. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Int J Surg*. 2010;8(5):336–341. doi:10.1016/j.ijsu.2010.02.007
21. Petticrew M, Egan M, Thomson H, Hamilton V, Kunkler R, Roberts H. Publication bias in qualitative research: what becomes of qualitative research presented at conferences? *J Epidemiol Community Health*. 2008;62(6):552–554. doi:10.1136/jech.2006.059394
22. Winch CJ, Sherman KA, Smith KM, Koelmeyer LA, Mackie H, Boyages J. “You're naked, you're vulnerable”: sexual well-being and body image of women with lower limb lymphedema. *Body Image*. 2016;18:123–134. doi:10.1016/j.bodyim.2016.06.002
23. Zhang JJ, Zhang Y. Qualitative study on delayed treatment of lower extremity moderate lymphedema after cervical cancer surgery. *Nurs Res*. 2020;34(2):303–306. doi:10.12102/j.issn.1009-6493.2020.02.025
24. Wang Y, Wang HM, Huang ZZ, Lou Y. A qualitative study on the real experiences of patients with lower extremity lymphedema after treatment of gynecological malignant tumors during the course of the disease. *Chinese J Rural Med Pharm*. 2021;28(8):63–64. doi:10.3969/j.issn.1006-5180.2021.08.03725
25. Jiang QH, Chen YM, He T. A qualitative study on experience of patients with lower extremity lymphedema after cervical cancer treatment. *Shanghai Nurs*. 2021;21(8):25–28. doi:10.3969/j.issn.1009-8399.2021.08.006
26. Li YL, Li MF, Wang YH, Tang W, Luo J. A qualitative study on the self-care experience of a patient with lower extremity lymphedema after cervical cancer surgery. *Psychol Magazine*. 2022;(20):177–178,226. doi:10.19738/j.cnki.psy.2022.20.056
27. Luo CX, Zhu L. A qualitative study on the self-management experience of patients with lower extremity lymphedema after gynecological tumor treatment at home. *Contemp Nurse*. 2023;30(7):60–63. doi:10.19791/j.cnki.1006-6411.2023.07.019
28. Seki K, Okutsu A. Suffering of patients developing lymphedema following gynecological cancer surgery. *J Rural Med*. 2023;18(4):205–214. doi:10.2185/jrm.2023-003
29. Yu XY, Chao YQ, Xie Q, Chen L. A qualitative study on CDT treatment compliance in patients with lower limb lymphedema after gynecological malignant tumor surgery. *Guide Chin Med*. 2024;22(34):13–16. doi:10.15912/j.issn.1671-8194.2024.34.004
30. Hsu YY, Liang PC, Hsu CF, Liu CY, Ho CL, Hsu KF. “I cannot walk far or go anywhere”: the experience of lower limb lymphedema among women with gynecological cancer. *Cancer Nurs*. 2024. doi:10.1097/NCC.0000000000001439
31. Zhang CN, Yang LZ, Shao QJ, Chen YY, Wu J. A qualitative study on delayed medical treatment of elderly patients with lower limb lymphedema after gynecological tumor surgery. *Chinese J Rural Med Pharm*. 2025;32(4):5–8. doi:10.19542/j.cnki.1006-5180.2404-584
32. Liu G, Liu Y, Hu J, Deng S, Fan J. Home self-management experience of gynaecological tumour patients with lower limb lymphoedema: a qualitative study. *Prim Health Care Res Dev*. 2025;26:e81. doi:10.1017/S1463423625100406
33. Tan Y, Yu C, Mo X, et al. Self-management of lower limb lymphedema at home following gynecologic cancer surgery: a qualitative study of women's experiences and challenges. *Front Psychol*. 2025;16:1728488. doi:10.3389/fpsyg.2025.1728488
34. Pervane Vural S, Ayhan FF, Soran A. The role of patient awareness and knowledge in developing secondary lymphedema after breast and gynecologic cancer surgery. *Lymphat Res Biol*. 2020;18(6):526–533. doi:10.1089/lrb.2020.0059
35. Schulz T, Lee Warg M, Kurow O, Langer S, Nuwayhid R. The burden of lymphedema on quality of life. *Vasa*. 2025;54(2):124–132. doi:10.1024/0301-1526/a001173
36. Cassidy T, Worrell CM, Little K, et al. Experiences of a community-based lymphedema management program for lymphatic filariasis in Odisha State, India: an analysis of focus group discussions with patients, families, community members and program volunteers. *PLoS Negl Trop Dis*. 2016;10(2):e0004424. doi:10.1371/journal.pntd.0004424
37. Oshiro M, Kamizato M. Patients' help-seeking experiences and delaying in breast cancer diagnosis: a qualitative study. *Jpn J Nurs Sci*. 2018;15(1):67–76. doi:10.1111/jjns.12173
38. Rashidi F, Abbasi M, Hamid Shabeeb H, Ahmadi N. Effect of family-centered empowerment program on quality of life and caregiving burden in family caregivers of patients with hematologic malignancies: a quasi-experimental study. *Eur J Oncol Nurs*. 2025;79:102996. doi:10.1016/j.ejon.2025.102996
39. Gokce E, Gun N, Duzlu Ozturk U, Dalyan M. Complex decongestive therapy improves gait speed in patients with lower limb lymphedema. *Lymphat Res Biol*. 2025;23(1):11–16. doi:10.1089/lrb.2024.0021

40. Bar L, Brandis S, Marks D. Improving adherence to wearing compression stockings for chronic venous insufficiency and venous leg ulcers: a scoping review. *Patient Prefer Adherence*. 2021;15:2085–2102. doi:10.2147/PPA.S323766
41. Yin Y, Lin J, Yang L, et al. Experiences of complete decongestive therapy for patients with lower limb lymphedema: a descriptive phenomenological study. *J Psychosom Res*. 2025;197:112351. doi:10.1016/j.jpsychores.2025.112351
42. Li M, Wang L, Zhang Y, Ding Y, Wang P. Behavioural trajectories of delay in seeking medical care in participants with breast cancer-related lymphoedema: a qualitative study. *BMJ Open*. 2025;15(9):e086805. doi:10.1136/bmjopen-2024-086805
43. Tumkaya MN, Seven M. Interventions for prevention and management of gynecological cancer-related lower limb lymphedema: a systematic scoping review. *Semin Oncol Nurs*. 2025;41(1):151781. doi:10.1016/j.soncn.2024.151781

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