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A Patient Journey Map for Lower Limb Lymphedema after Gynecologic Malignancy Surgery: A Qualitative Study

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A Patient Journey Map for Lower Limb Lymphedema after Gynecologic Malignancy Surgery: A Qualitative Study

Abstract

Background: Lower limb lymphedema (LLL) is a common and disabling long-term sequela of gynecologic cancer surgery, but the post-treatment experiences of affected women are poorly mapped. This study aimed to map the post-treatment journey of women with LLL and to identify their care tasks, emotional experiences, and unmet needs from preoperative counseling through long-term survivorship.

Methods: A qualitative descriptive study informed by the Systems Engineering Initiative for Patient Safety (SEIPS) 3.0 model. Fifteen women with LLL after surgery for endometrial (n = 8) or cervical (n = 7) cancer were recruited from a tertiary hospital in Fuzhou, China. Semi-structured interviews followed a five-stage journey framework, and data were analyzed using directed content analysis.

Results: The interviews followed five journey stages (preoperative awareness, postoperative monitoring, healthcare-seeking, treatment adaptation, and long-term coexistence), grouped for analysis into three phases (pre-diagnosis, diagnosis and treatment, and long-term coexistence); within each phase, three cross-cutting dimensions were examined: management tasks, emotional trajectories, and pain points. None of the participants recalled receiving preoperative lymphedema education; early symptoms were misattributed to chemotherapy or thrombosis, and time from symptom onset to diagnosis ranged from 3 months to 6 years. Treatment imposed heavy time and financial burdens. In the long term, women reported role conflict, social withdrawal, and persistent anxiety about progression. An exploratory cross-cutting observation, tentatively termed the "survivor optimism paradox," emerged across narratives: minimizing symptoms because cancer had been survived appeared to undermine self-management at all stages.

Conclusions: Survivors accumulate cognitive gaps, diagnostic system barriers, and broken long-term support. The journey map identifies stage-matched targets for care—structured preoperative education, standardized referral pathways, and planned

long-term follow-up—which should be embedded in routine women's health services rather than delivered as reactive treatment; such provision could shorten diagnostic delay and help women sustain self-management alongside family responsibilities.

Keywords: gynecologic cancer; lymphedema; patient journey map; qualitative research; health management; cancer survivorship

1. Introduction

The incidence of lower limb lymphedema (LLL) following surgery for cervical, endometrial, or ovarian cancer varies widely across cancer types and assessment methods, with reported rates of up to 56% [1] and nearly 70% when lymphadenectomy is combined with radiotherapy [2]. For many gynecologic cancer survivors, LLL is among the most prevalent concerns, second only to fear of recurrence [3]. LLL causes stiffness, numbness, heaviness, pain, and reduced limb function, leading to decreased quality of life, along with psychological issues such as depression, anxiety, and body image distress. Previous studies have shown that patients with lymphedema experience a distinct emotional trajectory after diagnosis [4]. Although the clinical and economic burden of LLL is well documented, less attention has been paid to how women experience care from diagnosis through long-term management.

The "patient journey" encompasses not only the clinical care pathway but also patients' needs, preferences, and experiences at each stage, and is typically illustrated using a patient journey map [5–7]. This patient-centered approach integrates emotions, behaviors, and needs to provide insights for improving the overall care experience [8]. The SEIPS 3.0 model (Systems Engineering Initiative for Patient Safety) provides a comprehensive framework to guide patient journey mapping, demonstrating how patients navigate key touchpoints and interact with six work system components:

person(s), tasks, tools and technologies, organization, internal environment, and external environment [9].

For gynecologic cancer survivors with LLL, the patient journey typically begins after pelvic surgery or radiotherapy and spans symptom recognition and initial diagnosis, acute treatment, maintenance and self-management, and long-term adaptation. At each phase, women experience distinct emotional responses—shock, fear of recurrence, frustration with ongoing self-care, and relief when symptoms stabilize—and key pain points include delayed diagnosis due to limited provider awareness, the high costs of compression garments and professional care, difficulty adhering to daily manual lymphatic drainage (MLD) and exercise, and limited social support. Complex decongestive therapy (CDT) is the current standard of care [11]: during the initial phase, therapists provide MLD until edema is substantially reduced, after which patients must sustain lifelong self-care, including MLD, functional exercise, skin care, and consistent use of compression garments. Although CDT can impede disease progression, it does not restore normal lymphatic function, requires costly professional care and garments, and adherence is poor; because lymphedema is a chronic, incurable condition [12], survivors require timely, lifelong self-management, yet many discontinue self-care when tasks are perceived as time-consuming or overly complex [13], and only about one-fifth fully adhere to recommended practices such as MLD and consistent garment use [14].

Although previous studies have addressed specific aspects of LLL management, a comprehensive investigation of the entire patient journey—integrating clinical, emotional, behavioral, and self-management dimensions—remains lacking. Most existing research focuses on either the immediate postoperative period or single-treatment efficacy, resulting in a fragmented understanding of the full disease trajectory. Therefore, this qualitative study aims to describe and explore the health management experiences, emotional responses, and needs of gynecologic cancer survivors with LLL throughout their entire journey. Guided by the SEIPS 3.0 model,

this study aims to identify the key interactions between different phases of the LLL journey and health management elements, using a qualitative descriptive design with directed content analysis. By constructing a patient journey map for LLL, this study aims to provide a foundation for developing targeted, personalized interventions that precisely address the unique needs of these women.

2. Methods

2.1 Design

A descriptive qualitative design was adopted to describe and explore participants' experiences [15]. This design is suitable for providing a comprehensive summary of events or experiences in participants' everyday language, without requiring a high level of interpretation [16]. Findings were reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [17] (Supplementary File 1).

2.2 Theoretical framework

This study was guided by the SEIPS 3.0 model [9]. The model extends the traditional structure-process-outcome framework by conceptualizing the "process" dimension as a patient journey—the spatio-temporal distribution of a patient's interactions with multiple care settings over time [9], and it positions patients' own self-management efforts as a form of patient work embedded in the sociotechnical system [10]. Each phase of the patient journey represents a local work system consisting of six interacting elements: person(s), tasks, tools/technologies, organization, internal environment, and external environment. These elements jointly influence patient outcomes across physical, emotional, behavioral, and social domains. The SEIPS 3.0 model was used to systematically analyze participants' experiences

across the lymphedema journey, identifying how work system barriers contribute to delayed diagnosis, poor self-management, and emotional distress.

2.3 Recruitment and participants

Fifteen women with LLL after surgery for endometrial (n = 8) or cervical (n = 7) cancer were recruited from the Lymphedema Diagnosis and Treatment Center of a tertiary hospital in Fuzhou, China, between December 2025 and March 2026, using purposive sampling. Inclusion criteria were: aged ≥ 18 years; gynecologic malignancy‐related LLL; ability to communicate effectively; and ability to provide written informed consent. To ensure that participants could describe the full treatment experience, only those who had completed at least three lymphedema treatment sessions were eligible. Patients with comorbid conditions precluding participation and those who had discontinued treatment were excluded. Eligible patients were approached face-to-face by research team members, and written informed consent was obtained before enrolment.

2.4 Data Collection

Semi-structured interviews were conducted by two trained female researchers (one with a master's degree; one a certified lymphedema therapist), neither of whom was involved in the participants' clinical care, in a quiet consultation room adjacent to the treatment room. The interview guide was developed from a literature review and refined through consultation with five gynecologic oncology experts. Each participant completed one audio-recorded interview lasting approximately 15‐30 minutes; only the participant and the interviewer were present, and non-verbal reactions were noted. Recordings were transcribed verbatim within 24 hours. All 15 invited participants completed the interview. Five transcripts were returned to participants for verification, and participant names were anonymized (P1‐P15). Clinical characteristics (cancer type, surgical procedure, adjuvant therapy, ISL stage, Stemmer sign, laterality and limb circumference) were obtained from the medical

record and the lymphedema clinic chart, and limb circumference was measured by a certified lymphedema therapist at each participant’s first pretreatment assessment.

2.5 Data Analysis

This study used directed content analysis, and all transcripts were managed and coded using NVivo software (QSR International, Melbourne, Australia). All interviews were transcribed verbatim in Chinese and read holistically to identify meaningful text units. Two researchers independently coded the transcripts and reached consensus through comparison and discussion, forming a preliminary coding scheme. Guided by the SEIPS 3.0 model and the patient journey framework (five stages: preoperative awareness, postoperative monitoring, healthcare-seeking, treatment adaptation, and long-term coexistence), codes were systematically categorized according to work system elements (person, tools, tasks, environment, organization) and patient outcomes (emotional, behavioral, physical, social function), along with three cross-cutting dimensions of health management (tasks, emotions, and pain points). Coding proceeded in two steps: transcripts were first coded openly line by line, and the resulting codes were then aggregated into categories and subcategories within the coding framework. Themes that could not be accommodated within the predefined framework were retained as emergent inductive codes—the cross-cutting observation later described as the “survivor optimism paradox” arose in this way. The final coding tree comprised four top-level categories corresponding to the major journey phases—preoperative experience, postoperative monitoring, healthcare-seeking and treatment, and self-management and life reconstruction—with subcategory nodes nested beneath each. Where coding disagreements persisted after discussion, they were adjudicated by a third researcher (Y.X.Y.). Data saturation was assessed by monitoring the emergence of new codes and subcategories across successive interviews: no new codes or subcategories were identified in the final three interviews (P13–P15), and this judgment was documented in analytic memos. We therefore considered the sample adequate in terms of both thematic saturation and

information power, while acknowledging that additional interviews might have revealed further experiences. Investigator triangulation and member checking were used to ensure trustworthiness. The final coding framework was integrated into a patient journey map to visually present the tasks, emotional trajectories, and pain points at each stage.

2.6 Reflexivity

The research team comprised nurses and rehabilitation specialists experienced in gynecologic oncology and lymphedema care; both interviewers were women and neither had a therapeutic relationship with the participants. Because the study was conducted in the hospital where participants received care, interviewers explicitly stated that participation was voluntary, that responses would not affect treatment, and that both positive and negative experiences were of interest, to minimize social desirability bias. Throughout the analysis, the team reflected on how clinical assumptions might shape interpretation, and preliminary interpretations were repeatedly checked against the original transcripts until consensus was reached.

2.7 Ethical Approval

This study was strictly conducted in accordance with the ethical principles of the Declaration of Helsinki. The research protocol was approved by the Ethics Committee of Fujian Provincial Maternity and Child Health Hospital (approval number: 2024KY266). Prior to the formal interview, all participants were informed of the purpose and importance of the study and signed written informed consent forms. The researchers clearly stated that participants had the right to withdraw at any stage of the study; all information would be kept strictly confidential and stored in encrypted form; and all identifiable personal information would be anonymized.

3. Results

3.1 Participant Characteristics

Fifteen women with lower limb lymphedema after gynecologic cancer surgery participated; all had undergone hysterectomy with pelvic lymph node dissection (eight for endometrial cancer and seven for cervical cancer). The mean age was 59.9 years (range 50–73). Most had a middle school education or below (60.0%), were retired or unemployed (80.0%), and lived in urban areas (66.7%). Median time from surgery to first symptom onset was 4 months; median time from symptom onset to diagnosis was 6 months (range 3 months to 6 years). Twelve received adjuvant chemotherapy (80.0%), eight received radiotherapy (53.3%), and two had no adjuvant therapy (Table 1). The two groups differed in surgical approach: six of the seven women with cervical cancer underwent radical hysterectomy, whereas all eight with endometrial cancer underwent simple hysterectomy; radiotherapy was given to four women in each group (Table 1). Lymphedema was staged by clinical assessment according to the International Society of Lymphology (ISL) criteria: three participants had stage I, eleven stage II, and one stage III lymphedema, and the Stemmer sign was positive in thirteen. Lymphedema affected the left lower limb in ten participants and the right in five; none had bilateral involvement. All participants had received complex decongestive therapy (CDT). At the initial pretreatment assessment, the largest affected-to-contralateral circumference difference across the five measured levels ranged from 3.0 to 11.0 cm (median 6.0 cm).

Table 1 Demographic and clinical characteristics of participants (N = 15)

ID	Age (years)	Education	Occupation	Residence	Cancer type and surgery	Adjuvant therapy	LLL stage (ISL) / Stemmer sign	Laterality	Max circumference difference (cm)	LLL treatment	Lymphedema duration
P1	62	Middle school	Retired	Urban	Endometrial cancer, hysterectomy + PLND	Chemotherapy	Stage III (ISL); Stemmer sign positive	Left	6.0	CDT	3 years
P2	60	High	Retired	Urban	Endometrial	Chemotherapy	Stage II (ISL);	Left	5.9	CDT	1 year

		school			cancer, hysterectomy + PLND		Stemmer sign positive				
P3	61	Bachelor	Retired	Urban	Cervical cancer, radical hysterectomy + PLND	Chemotherapy	Stage II (ISL); Stemmer sign positive	Left	6.8	CDT	3 months
P4	62	High school	Retired	Town	Endometrial cancer, hysterectomy + PLND	Chemotherapy	Stage I (ISL); Stemmer sign negative	Left	5.5	CDT	3 years

P5	60	Middle school	Unemployed	Urban	Endometrial cancer, hysterectomy + PLND	Chemotherapy	Stage I (ISL); Stemmer sign positive	Right	3.0	CDT	6 months
P6	62	Associate	Unemployed	Urban	Endometrial cancer, hysterectomy + PLND	Chemotherapy + Radiotherapy	Stage II (ISL); Stemmer sign positive	Left	11.0	CDT	6 months
P7	62	Primary school	Unemployed	Urban	Endometrial cancer, hysterectomy + PLND	Chemotherapy + Radiotherapy	Stage II (ISL); Stemmer sign positive	Left	3.4	CDT	1 year

P8	67	Primary school	Unemployed	Urban	Endometrial cancer, hysterectomy + PLND	Chemotherapy + Radiotherapy	Stage II (ISL); Stemmer sign positive	Left	6.0	CDT	1 month
P9	50	High school	Self-employed	Urban	Cervical cancer, hysterectomy + PLND	−	Stage II (ISL); Stemmer sign positive	Right	7.5	CDT	1 month
P10	54	Middle school	Self-employed	Urban	Cervical cancer, radical hysterectomy + PLND	Chemotherapy + Radiotherapy	Stage II (ISL); Stemmer sign positive	Right	10.4	CDT	6 years

P11	56	Middle school	Unemployed	Town	Cervical cancer, radical hysterectomy + PLND	−	Stage II (ISL); Stemmer sign positive	Left	9.3	CDT	2 months
P12	61	Primary school	Unemployed	Town	Endometrial cancer, hysterectomy + PLND	Radiotherapy	Stage II (ISL); Stemmer sign positive	Left	5.2	CDT	5 years
P13	73	Primary school	Unemployed	Town	Cervical cancer, radical hysterectomy	Chemotherapy + Radiotherapy	Stage II (ISL); Stemmer sign positive	Left	3.0	CDT	1 year

					+ PLND						
P14	50	Bachelor	Self-employed	Urban	Cervical cancer, radical hysterectomy + PLND	Chemotherapy + Radiotherapy	Stage II (ISL); Stemmer sign positive	Right	7.6	CDT	6 months
P15	59	Primary school	Unemployed	Town	Cervical cancer, radical hysterectomy + PLND	Chemotherapy + Radiotherapy	Stage I (ISL); Stemmer sign negative	Right	3.0	CDT	2 years

PLND: pelvic lymph node dissection. The number of harvested lymph nodes was not recorded in this cohort. LLL staging was based on clinical assessment according to the International Society of Lymphology (ISL) criteria; Stemmer sign was assessed at the toes. All participants received complex decongestive therapy (CDT). Limb circumference was measured with a tape measure on both limbs at five levels—above the middle toe, above the lateral malleolus, at the inferior border of the patella, and 10 and 20 cm above the superior border of the patella—at the initial pretreatment assessment, and the largest affected–contralateral difference across these levels is reported; volumetric measurement was not performed.

3.2 Description of the LLL Patient Journey

The patient journey was divided into three phases: pre-diagnosis (preoperative awareness and postoperative monitoring), diagnosis and treatment (healthcare-seeking and treatment adaptation), and long-term coexistence; the five journey stages derived from the interview guide (Supplementary Table S1) were grouped analytically into these three phases. The four coding categories described in Section 2.5 were consolidated for presentation in the same way: preoperative experience and postoperative monitoring form the pre-diagnosis phase, healthcare-seeking and treatment form the diagnosis-and-treatment phase, and self-management and life reconstruction forms the long-term coexistence phase. Analysis focused on three dimensions—health management tasks, emotional states, and pain points—with pain points escalating across phases: from cognitive gaps, to system barriers, to broken long-term support. Twenty-three subcategories were identified across the three phases, together with the cross-cutting pattern described in Section 3.2.4. The patient journey map (Figure 1) visualizes challenges and emotional changes; Table 2 presents the full categories and subcategories.

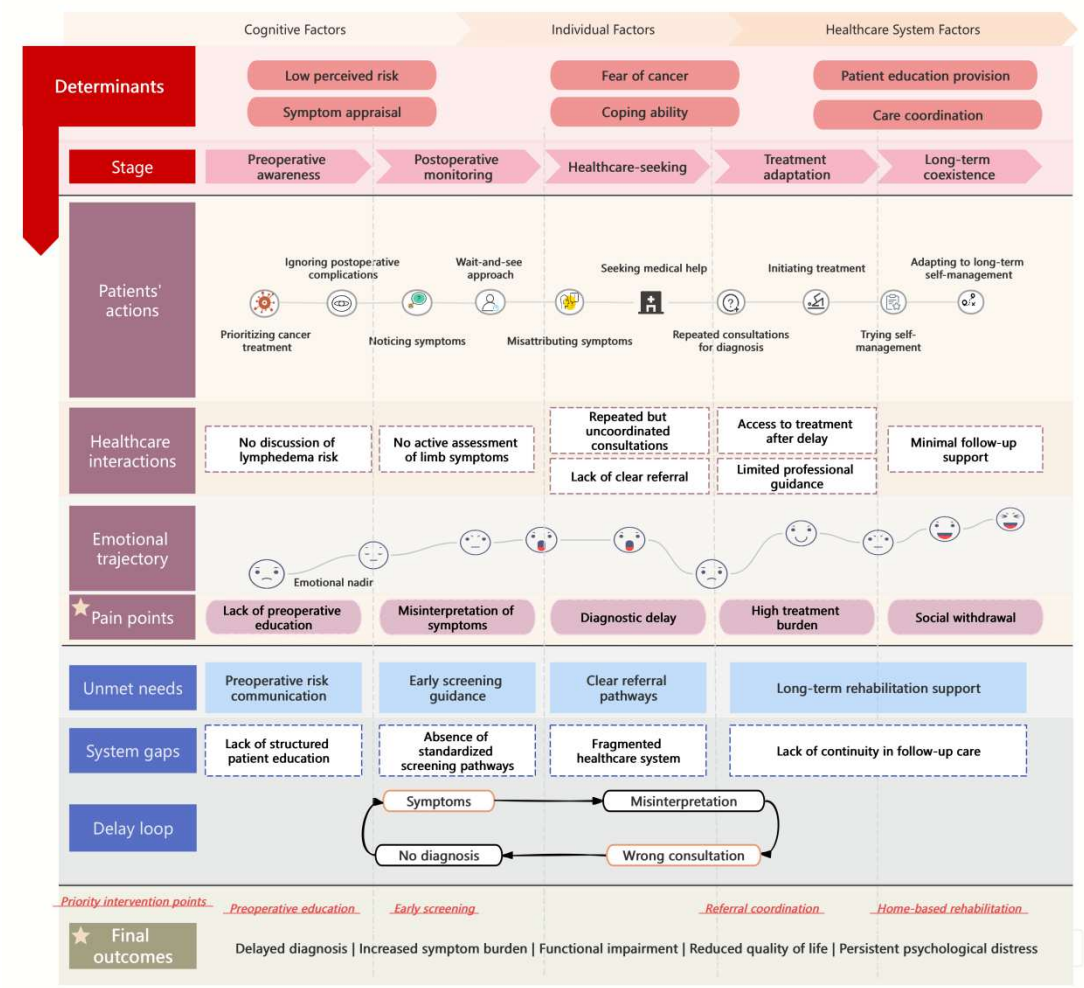


Figure 1. Patient journey map for lower limb lymphedema after gynecologic cancer surgery. The map integrates the five journey stages (preoperative awareness, postoperative monitoring, healthcare-seeking, treatment adaptation, and long-term coexistence) with patients' actions, healthcare interactions, emotional trajectory, and pain points across cognitive, individual, and healthcare-system determinants, and summarizes unmet needs, system gaps, the delay loop, priority intervention points, and final outcomes, as organized by the SEIPS 3.0 model.

Table 2. Summary of themes and subthemes

Stage	Core Category	Subcategories	Subthemes	Quotes	Participant ID
Pre-diagnosis Phase	Tasks	Acquiring surgical risk information and making treatment decisions	Lack of preoperative education	*"If you told me that after the surgery I would have swelling for the rest of my life, then I would have thought carefully about whether so many nodes needed to be removed."*	*P4*
				"The conversation at that time focused on whether to do a full resection and how much to remove. Lymphedema was not yet placed in a very important position."	*P5*
				"No, none at all. The doctor just told me they would decide during the operation."	*P4*

		Identifying and attributing early postoperative abnormalities	Misattribution to chemotherapy or normal recovery	*"My toes were numb… I thought it was caused by chemotherapy."*	*P5*
				"The first time I felt something was wrong… I thought it was because of the surgery."	*P4*
				"After chemotherapy, I first felt pain, and then one or two months later my foot started to swell."	*P1*
	Emotions	Confusion and selective neglect	Wait-and-see attitude	*"There was no panic. I wasn't especially afraid. I just thought, if there was a problem, I would deal with it."*	*P2*
				"At that time I didn't pay attention. I thought it didn't matter. Some people said swelling would go down later."	*P9*

	Pain Points	Lack of lymphedema education	No explicit warning from providers	*"The doctor explained everything, but because we were ignorant, sometimes we didn't pay attention or couldn't remember."*	*P1*
				"At first I didn't understand these things. Later, when my leg swelled, I heard it was lymphedema."	*P9*
		Misinterpretation and attribution bias regarding symptoms	Symptoms attributed to standing, fatigue, or treatment side effects	*"I thought it was because I stood too long or sat too long."*	*P2*
				"I suspected it was a side effect of radiotherapy and chemotherapy."	*P7*
		Unsafe self-management behaviors	Heat therapy, foot soaking, moxibustion	*"After I became swollen, the doctor at the Chinese medicine hospital told me to soak my feet."*	*P2*

				"Last year I had moxibustion, but they said I shouldn't do it because my leg is afraid of heat."	*P6*
				"The doctor suggested I go back and try traditional Chinese medicine or acupuncture."	*P12*
Diagnosis and Treatment Phase	Tasks	Seeking diagnosis across multiple departments	Diagnostic delay and system barriers	*"My leg was swollen for three years before I was diagnosed with lymphedema… Every ultrasound was normal."*	*P7*
				"The doctor said to observe it and see whether it would go down after six months and recover on its own."	*P7*
				"Doctors from Peking Union Medical College Hospital came to consult, but no one told me the exact cause."	*P1*

	Receiving CDT and learning self-management	Gaps in home care guidance	*"The head nurse taught me how to do the massage… Since I come every day, there's no need for me to measure it again at home."*	*P1*
			"No, none at all. I just looked with my eyes to see whether it was swollen."	*P3*
Emotions	Frustration, helplessness, and relief after diagnosis	Relief at finally having an answer	*"That's good at least. At least I know this can happen after surgery."*	*P7*
			"I felt a bit relieved, like a big stone had been lifted from my heart."	*P12*
	Fatigue under time and financial pressure	Daily travel burden and out-of-pocket costs	*"Of course there was pressure. In terms of time, it was hard to take leave. Financially, it also increased the burden, by more than 1,000 yuan a month."*	*P4*

				"The round trip takes nearly two hours because the distance is relatively far."	*P1*
		Family dynamics: guilt and reassurance	Guilt over being a burden vs. encouragement from family	*"Once someone in the family gets sick, it feels like we're back to square one… I feel like I'm adding burden to the children."*	*P6*
				"It was my husband—he pushed me to come. He said I absolutely had to come for treatment."	*P2*
	Pain Points	Diagnostic delay and systemic barriers	No standardized referral pathway	*"At that time I was receiving PD-1 treatment in Macau… Over there, treatment was still mainly surgery-based, and there was no such follow-up care."*	*P10*
		Informal information networks compensating for missing referrals	Douyin, WeChat, family online search	*"I saw related content on Douyin recently and thought I might have it too, so I came quickly."*	*P5*

			"My grandson searched online and found that this hospital provided the treatment."	*P14*
			"Later my niece saw the head nurse's Moments post and introduced me to the lymphedema clinic."	*P13*
	Lack of self-management knowledge	No guidance on measurement, exercise, or garment selection	*"No, I didn't know anything at all. We needed guidance on these things."*	*P9*
			"I don't remember, and I didn't really know. We need this kind of support."	*P14*
	Insufficient insurance coverage	Poor reimbursement for rehabilitation and materials	*"Medical insurance doesn't reimburse much, not even half."*	*P4*
			"Treatment and consumables such as gauze	*P13*

				and taping are often not reimbursed."	
		Physical barriers to compression therapy	Discomfort, sleep disturbance, heat, allergy	*"When I was wrapped in bandages… my leg feeling like wood, I can't sleep."*	*P2*
				"It's inconvenient to wear and bandage, and it's very uncomfortable in hot weather."	*P13*
				"I was told to wear compression garments, but I didn't wear them."	*P14*
Long-term Coexistence Phase	Tasks	Maintaining treatment effects while balancing family roles	Role conflict: self-care vs. family duties	*"It affects me a lot… I used to do a lot of things, but now I can't stand for long."*	*P4*
				"I can't take care of the grandchildren anymore… I tried for three days, and then I couldn't manage at all."	*P6*

	Restricted social participation	Reduced travel and social gatherings	*"It's very difficult now. Traveling and things like that are all very hard."*	*P4*
			"I hardly go out anymore."	*P2*
Emotions	Fluctuating anxiety	Fear of progression and complications	*"My main concern is the long-term progression, like what will happen in ten or twenty years."*	*P4*
			"I worry a little. I'm afraid it will swell again… because there's no cure."	*P3*
	Social isolation and reduced sense of self-worth	Withdrawal and loss of meaning	*"I don't really want to see people now."*	*P3*
			"I don't really want to see people like this now… I have no mood, no spirit."	*P2*

	Pain Points	Lack of follow-up support after discharge	No proactive monitoring	*"No one told me in advance what I should watch for."*	*P5*
				"So we have to observe it ourselves, right?"	*P3*
		Role conflict: chronic patient versus primary family caregiver	Family attention fades; patient feels "forgotten"	*"Ordinary families won't pay much attention to the mother's condition anymore."*	*P2*
		Lack of social awareness and health education	Low public knowledge; calls for better education	*"The publicity is not enough. I didn't know about this disease at all before."*	*P10*
				"I think you need to strengthen education about lymphedema, especially after chemotherapy."	*P1*
Cross-cutting Driver	Cognitive Paradox	The "Survivor" Optimism Paradox	Minimizes symptoms pre-diagnosis; reduces adherence during	*"I'm a relatively strong person. I don't worry too much about major or minor*	*P1*

	treatment; erodes long-term self-management	*illnesses."*	
Cross-cutting Pattern		*"If I survived the threshold of death, then I should just take it easy."*	*P9*
		"My mindset is still okay. I thought it would metabolize away on its own over time."	*P5*
		"No, I wasn't anxious and didn't struggle much. I just thought, if it can be treated, then treat it; if not, then so be it."	*P10*

3.2.1 Pre-diagnosis Phase

Tasks

Acquiring information about surgical risk and making treatment decisions

Before surgery, participants had to weigh cancer control against functional preservation. However, the vast majority reported that they received no targeted explanation from healthcare professionals regarding the risk of lymphedema. Some participants recalled that physicians mentioned it only briefly and vaguely, without leaving a meaningful impression. Several noted that had they known lymphedema could cause lifelong swelling, they might have reconsidered the extent of lymph node dissection: *"If you told me that after the surgery I would have swelling for the rest of my life, then I would have thought carefully about whether so many nodes needed to be removed" (P4)*.

Identifying and attributing early postoperative abnormalities

During postoperative recovery and chemotherapy, participants began to notice various limb abnormalities, including numbness in the toes, unilateral warmth in the sole, leg tightness and pain, and visible swelling. However, most attributed these symptoms to chemotherapy side effects, overwork, or what they believed to be normal postoperative reactions. Very few associated them with lymphedema: *"My toes were numb… I thought it was caused by chemotherapy" (P5).*

Emotions

Confusion and selective neglect

Faced with sudden abnormalities, participants felt confused but tended to adopt a wait-and-see approach, believing symptoms would resolve on their own: *"There was no panic… I just thought, if there was a problem, I would deal with it" (P2).*

Pain Points

Lack of lymphedema education

No participant recalled receiving a clear explanation of lymphedema risk, manifestations, or long-term impact before surgery: *"The doctor explained everything, but because we were ignorant, sometimes we didn't pay attention or couldn't remember" (P1)*.

Misinterpretation and attribution bias

Because participants did not know about lymphedema, they attributed early symptoms to chemotherapy neurotoxicity, radiotherapy effects, prolonged standing or sitting, or general postoperative fatigue. This cognitive bias directly delayed care-seeking :*"I thought it was because I stood too long or sat too long." (P2)*

Unsafe self-management behaviors

Some patients adopted contraindicated interventions such as hot-foot soaking or moxibustion: *"After I became swollen, the doctor at the Chinese medicine hospital told me to soak my feet" (P2)*. These practices may worsen lymphatic load.

3.2.2 Diagnosis and Treatment Phase

Tasks

Seeking diagnosis across multiple departments

When symptoms persisted, participants began to seek medical care. Repeated venous ultrasounds ruled out thrombosis but offered no diagnosis, and no referral pathway existed: *"My leg was swollen for three years before I was diagnosed with lymphedema… Every ultrasound was normal" (P7).*

Receiving CDT and learning self-management

After diagnosis, patients needed to travel to the hospital daily or several times a week to receive manual lymphatic drainage and multilayer compression bandaging. They were also expected to learn home self-management skills: *"Since I come every day, there's no need for me to measure it again at home" (P1).*

Emotions

Frustration, helplessness, and relief after diagnosis

The long diagnostic process left patients helpless, yet confirmation brought relief: *"I felt a bit relieved, like a big stone had been lifted from my heart" (P12)*.

Fatigue under time and financial pressure

Daily travel (1.5 hours each way), work leave, and out-of-pocket costs created heavy burdens: *"In terms of time, it was hard to take leave. Financially, it also increased the burden, by more than 1,000 yuan a month" (P4)*.

Family dynamics: guilt and reassurance

Family played a dual role—guilt over being a burden coexisted with encouragement: *"Once someone in the family gets sick… I feel like I'm adding burden to the children" (P6).* A husband's urging or a daughter's help often motivated continued attendance.

Pain Points

Diagnostic delay and systemic barriers

Delays ranged from 3 months to 6 years, due to the absence of referral pathways and physicians focusing solely on excluding thrombosis: *"Over there, treatment was still mainly surgery-based, and there was no such follow-up care" (P10).*

Informal networks compensating for missing referrals

When formal systems failed, social media and family online searches often triggered diagnosis: *"I saw related content on Douyin recently and thought I might have it too, so I came quickly" (P5)*.

Lack of self-management knowledge and skills

Most patients knew little about home management—measurement, garments, or exercise: *"No, I didn't know anything at all. We needed guidance on these things" (P9)*.

Insufficient insurance coverage

Rehabilitation services and materials were poorly reimbursed: *"Medical insurance doesn't reimburse much, not even half" (P4)*.

Physical barriers to compression therapy

Discomfort—tight bandaging, heat, and allergy—undermined adherence: *"When I was wrapped in bandages… my leg feeling like wood, I can't sleep" (P2)*.

3.2.3 Long-term Coexistence Phase

Tasks

Maintaining treatment effects while balancing family roles

Patients struggled to maintain gains while resuming household duties; self-care was often deprioritized: *"I can't take care of the grandchildren anymore… I tried for three days, and then I couldn't manage at all" (P6)*.

Restricted social participation

Swelling, limited mobility, and visible garments reduced social activities: *"It's very difficult now. Traveling and things like that are all very hard" (P4)*.

Emotions

Fluctuating anxiety

Even when stable, anxiety persisted, triggered by visible swelling or fear of complications: *"My main concern is the long-term progression, like what will happen in ten or twenty years" (P4)*.

Social isolation and reduced self-worth

Unable to participate in previous activities, patients felt marginalized: *"I don't really want to see people like this now… I have no mood, no spirit" (P2)*.

Pain Points

Lack of follow-up support after discharge

No proactive monitoring existed after discharge: *"No one told me in advance what I should watch for" (P5)*.

Role conflict between chronic patient and family caregiver

As family attention shifted, patients felt forgotten: *"Ordinary families won't pay much attention to the mother's condition anymore" (P2)*.

Lack of social awareness and health education

Public and provider awareness was low; patients called for better education: *"I think you need to strengthen education about lymphedema, especially after chemotherapy" (P1)*.

3.2.4 Cross-cutting Pattern: The "Survivor" Optimism Paradox

Across all three phases, a recurrent pattern—which we provisionally term the "survivor optimism paradox"—shaped how women interpreted and acted on lymphedema. Two components appeared to interact. The first was minimization grounded in having survived cancer: because the illness and its treatment had been endured, leg swelling was construed as comparatively trivial and therefore not worth attention. The second, less often articulated, was reluctance to re-engage with the illness: once surgery was judged successful and time had passed, participants described their bodies as gradually recovering and were unwilling to revisit the possibility of recurrence—an unwillingness that extended to acknowledging that the current swelling might be a consequence of the cancer and the operation. Together, these components operated as a double-edged sword: they supported endurance during cancer treatment, but they delayed recognition and undermined sustained self-management of lymphedema.

During postoperative monitoring, minimization was compounded by misattribution. Swelling was read as a predictable consequence of treatment already endured—chemotherapy, radiotherapy, or the operation itself—or as something transient that would settle on its own, and several participants recalled noticing the leg but deciding that no action was required.

"I just felt it should be the effect of radiotherapy and chemotherapy." (P6)

"I just felt my leg was tight, and it became more and more obvious later. I initially thought it was a blood clot." (P7)

"I'm a relatively strong person. I don't worry too much about major or minor illnesses. I didn't understand how serious it was. If I had known, I would have sought treatment immediately." (P1)

At the point of healthcare-seeking, the same stance appeared as a form of psychological protection. Having already confronted a life-threatening illness, participants met a non-life-threatening complication with fatalistic equanimity: some described letting go of worry altogether, others relief at having one less battle to fight, and several an explicit decision not to dwell on the illness again.

"At that time it could only be like that, and I was a bit self-defeating. I didn't think too much, I just felt there was nothing to be done." (P9)

"I felt a bit relieved, as if I had put down a heavy stone." (P11)

"I tried not to think about it and to move on as quickly as possible." (P4)

During long-term coexistence, the pattern re-emerged as a barrier to sustained self-management. Participants who had coped with cancer by "letting it be" applied the same stance to lymphedema, attributing persistent swelling to gradual postoperative recovery or to ageing and underestimating its progressive course. The reluctance to revisit the illness persisted into daily life, leaving several disinclined to monitor or treat the affected limb.

"My mindset is still okay. I thought it would metabolize away on its own over time." (P5)

"No, I wasn't anxious and didn't struggle much. I just thought, if it can be treated, then treat it; if not, then so be it." (P10)

The pattern was prevalent but not uniform. Eleven of the fifteen participants described at least one of these components in their own words, whereas P8 marks the limit of the pattern: she was the only participant who interpreted the swelling as possible metastatic disease and worried accordingly, yet when surgery was discussed she moved to the same fatalism, accepting the operation without considering what would follow. The remaining three participants did not articulate the pattern at all. We therefore describe it as a tendency of varying strength along the pathway rather than as a characteristic shared by the whole sample, and we do not treat it as a psychological type.

"I might worry about whether it has metastasized again." (P8) — and later, on treatment: "If it can be treated, I'll treat it; if not, I'll let it be."

Minimization, avoidance, and normalization overlap in participants' narratives and the boundary between them is not sharp; we use the term as a shorthand for the accounts above rather than as a construct to be measured. Clinically, it suggests that lymphedema education may need to be delivered separately from cancer-related education—acknowledging the achievement of survival while making the risk of a late effect explicit—so that women neither dismiss swelling as trivial nor experience renewed fear of recurrence.

4. Discussion

In this study, we constructed a patient journey map for women with lower limb lymphedema (LLL) after gynecologic cancer surgery, offering insights into their task burden, emotional trajectory, and evolving pain points. Most existing studies have focused on single-time-point barriers, overlooking how pain points cumulatively escalate across phases [18–22]. Moreover, culturally embedded maladaptive

behaviors and the “survivor” cognitive paradox remain underexplored. Extending the SEIPS 3.0 framework, our study reveals that LLL pain points dynamically accumulate: from cognitive gaps (no preoperative education), to systemic diagnostic mazes (no referral pathways), to broken long-term support (no follow-up, shifting family attention). We are not aware of a previous study that has mapped the full post-treatment journey of LLL in gynecologic cancer survivors within the SEIPS 3.0 framework, and our findings reframe lymphedema from a reactive complication of cancer treatment into a longitudinal priority for survivorship care.

The composition of the sample also bears on interpretation. Cervical and endometrial cancers differ in surgical radicality and in the field and dose of adjuvant radiotherapy, both of which influence lymphatic injury, yet the narratives were strikingly similar across the two groups: the same sequence of unrecognized swelling, repeated consultations without a diagnosis, relief at finally being told what was wrong, and difficulty sustaining self-care recurred in both. This convergence suggests that the care gaps we identified are organized around how the health system responds to lymphedema rather than around the specific oncological treatment a woman received.

Guided by the SEIPS 3.0 model, we identified work system interactions across each phase. In the pre-diagnosis phase, the “organization” element (preoperative disclosure not including lymphedema) and the “person” element (surgeons not mentioning risk) jointly resulted in patients’ complete lack of awareness, likely because surgical teams prioritize cancer control over functional outcomes. This “cognitive gap” led to misattribution of early postoperative signals (numbness, swelling) to chemotherapy or fatigue, and the early intervention window was missed. Similar findings are reported in breast cancer-related lymphedema research [23]. Non-specialist providers also lack lymphedema knowledge [24], underscoring the need for education programs—such as workshops by certified therapists—for oncology and gynecology teams. The extent of pelvic lymphadenectomy remains debated: in node-negative early-stage endometrioid endometrial cancer, pelvic and para-aortic lymphadenectomy conferred no survival benefit [33], whereas lymph node count retains prognostic significance [34]. Surgical decision-making therefore

requires balancing oncological benefit against postoperative morbidity, including lymphedema—reinforcing the importance of the preoperative risk education highlighted in our journey map.

In the diagnosis and treatment phase, multiple elements interacted to cause diagnostic delays. The "tools" (venous ultrasound ruling out thrombosis but unable to diagnose lymphedema), "organization" (no cross-department referral), and "person" (non-specialist physicians unfamiliar with lymphedema) jointly resulted in delays of 3 months to 6 years (median 6 months). This "diagnostic maze" delayed treatment and exacerbated distress. While CDT is the gold standard [11] and Chinese guidelines for postoperative lymphedema care were issued in 2021 [25], standardized management remains incomplete [26]. Our findings reveal a clear deficiency in early recognition and referral pathways.

Work system pressures during treatment adaptation were equally prominent. The "environment" (long travel distances), "organization" (low insurance reimbursement), and "task" (daily commuting, learning self-management) jointly imposed significant time and financial burdens. This aligns with reports that lymphedema treatment costs impose substantial financial strain on families [27]. Within China's healthcare system, formal in-home support is limited; caregiving falls on family members, intensifying patients' guilt and creating an environment where patients' own health needs are deprioritized.

In the long-term coexistence phase, work system support breakdown is evident—with no hospital follow-up, shifting family attention, and limited community awareness. This role transition—from caregiver to care recipient—was observed by Zhang et al. [22] in cervical cancer patients, but our findings extend these observations by revealing that guilt persists and intensifies as family attention shifts away. When disease management conflicted with family responsibilities, patients prioritized the latter, leading to poor adherence. Regular follow-up is essential to ensure patients engage in self-management, as long-term maintenance plays a pivotal role in minimizing lymphedema risk [28].

Our emotional trajectory analysis showed that patients experienced confusion

and neglect pre-diagnosis, frustration mixed with relief and anxiety during diagnosis and treatment, and persistent progression anxiety and social isolation during long-term coexistence. This pattern is consistent with previous findings [29]. Patients with lymphedema face greater psychological stress than those without, which may exacerbate symptom perception and self-management difficulties [30]. Thus, psychological support is crucial. Participants also called for enhanced health education targeting patients, families, and the broader community to facilitate early detection and support adherence.

Taken together, these findings support several stage-matched strategies. Preoperatively, brief structured education—covering personal risk factors (particularly the extent of lymphadenectomy) and early warning signs such as unilateral swelling, limb heaviness, or numbness—could be integrated into existing preoperative counseling. Postoperatively, risk-adapted surveillance (for example, limb circumference measurement at routine oncology follow-up visits) and a clearly defined referral pathway from oncology clinics to certified lymphedema services could shorten diagnostic delay. In the maintenance phase, affordable compression garments, home-based self-management programs, and follow-up delivered through community health services or online platforms may reduce the burden of frequent hospital visits. Consistent with recent narrative reviews on secondary lymphedema prevention in gynecologic cancer care [35], education before surgery and structured surveillance are the most consistently recommended strategies. The feasibility of these strategies differs across health systems: in China, embedding lymphedema follow-up within existing community-based chronic disease management may be more realistic than building new specialized services, whereas high-resource settings may sustain multidisciplinary lymphedema programs. These proposals are hypothesis-generating; as a qualitative study, our design can identify unmet needs and care gaps but cannot establish the effectiveness of specific interventions, which requires prospective evaluation.

Treatment intensity also varied. All participants received CDT, but the number of sessions, the frequency of professional follow-up, and the supply of compression

garments differed, and several women described cost and travel as reasons for irregular attendance. Because treatment was delivered according to clinical need rather than a standardized protocol, we cannot determine how intensity shaped symptom burden; what the narratives do show is that the effort of sustaining treatment was itself a recurring pain point.

Dietary supplementation and micronutrient status were not examined in this study, and we make no claims about them. Although nutritional factors may influence tissue healing and symptom experience, they fall outside the scope of a journey-mapping study concerned with care tasks and system barriers.

The interpretations above rest on our interview data alone; the comparison that follows draws on evidence from other settings and is offered as triangulation rather than confirmation. Evidence from other settings points in a similar direction: recent research published in Journal of Cancer Survivorship identified awareness, access, and financial burden as the three core challenges of cancer-related lymphedema care among survivors and healthcare professionals in Australia [31], and reported that self-management support, patient empowerment, and a structured surveillance roadmap are among survivors' highest priorities in Canada [32]. Our findings converge with these reports but extend them in three respects. First, by mapping the journey longitudinally, we show that these challenges are not independent but cumulative: the awareness gap established before surgery shapes how early symptoms are attributed, which prolongs the diagnostic maze and, in turn, erodes adherence during long-term coexistence. Second, whereas most lymphedema research has been conducted in breast cancer populations, we focus on gynecologic cancer survivors, in whom pelvic lymph node dissection, lower limb involvement, and the coexistence of genital and lower limb symptoms generate distinct survivorship needs. Third, we describe a non-Western health system in which the absence of formal referral pathways is partly compensated by informal information networks such as Douyin and WeChat—a double-edged mechanism that shortens delay for digitally connected survivors while leaving those without such resources behind. Together, these observations position LLL as a survivorship care issue that requires planned,

longitudinal follow-up rather than reactive, episodic treatment.

Limitations

This study has several limitations. First, participants were recruited from a single specialized lymphedema center and were required to have completed at least three treatment sessions; women who were never diagnosed, could not access specialized care, or discontinued treatment because of financial or logistical barriers were therefore not represented. Because such women may face the greatest barriers, our findings likely underestimate the difficulties experienced by the most vulnerable patients, and the transferability of the findings to other settings, younger survivors, or resource-constrained contexts is limited. The number of women screened but ineligible, or who declined to take part, was not systematically recorded, so the size of this selection bias cannot be quantified. Second, the interviews lasted 15–30 minutes, which may have limited the depth of some accounts; nevertheless, no new codes emerged from the final interviews, and consistent patterns recurred across participants. Third, participants retrospectively recounted experiences that in some cases had occurred years earlier; recall bias may therefore affect descriptions of preoperative counseling, symptom onset, and diagnostic delay. In particular, the observation that no participant recalled receiving preoperative lymphedema education reflects what participants remembered rather than objectively verifying what information was provided, and it should be interpreted accordingly. Limb circumference was recorded, but volumetric measurement was not performed, so the reported differences may not fully capture the magnitude of swelling. The number of lymph nodes removed at lymphadenectomy was not recorded in this cohort, although all participants underwent pelvic lymph node dissection; we were therefore unable to examine whether the extent of nodal harvest was related to the experiences described. We also did not assess menopausal status and symptoms, pelvic organ prolapse, or urinary incontinence. These conditions frequently coexist after gynecologic cancer treatment and may compound symptom burden and the demands of self-management, so their contribution to the experiences described here could not be examined. Women treated for ovarian cancer were not included either, for a practical reason: during the study

period no patient with ovarian cancer–related lower limb lymphedema presented at our center, which treats a small number of women with this diagnosis, partly because ovarian cancer is often detected at an advanced stage and carries a comparatively poor prognosis, so fewer survivors live long enough to receive lymphedema care. The journey of these women may differ in important respects and warrants separate study. Finally, the "survivor optimism paradox" is an exploratory interpretation derived from qualitative narratives rather than an established psychological construct; its prevalence, conceptual boundaries, and distinction from normalization, avoidance, and minimization warrant examination in future research.

5. Conclusion

This study constructs a patient journey map for women with LLL after gynecologic cancer surgery, identifying three phases of cumulative pain points—cognitive gaps, diagnostic system barriers, and broken long-term support—along with an exploratory cross-cutting observation, tentatively termed the "survivor optimism paradox." The journey map suggests stage-matched targets for care—preoperative lymphedema education, standardized referral pathways, and structured long-term follow-up—whose effectiveness should be evaluated in prospective studies.

Declarations

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Consent to participate: Informed consent was obtained from all individual

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Consent for publication: The authors affirm that human research participants provided informed consent for publication of the data included in this manuscript.

Availability of data and materials: The datasets generated during and/or analysed during the current study are not publicly available due to ethical restrictions but are available from the corresponding author on reasonable request.

Authors' contributions: Yueqi Chao: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing – original draft. Shuman Chen: Investigation, Data curation, Formal analysis, Writing – review & editing. Ling Chen: Validation, Formal analysis, Writing – review & editing. Xiaoyan Yu: Conceptualization, Supervision, Project administration, Writing – review & editing (Corresponding author). All authors read and approved the final manuscript.

Additional files

Additional file 1: Supplementary Table S1 (semi-structured interview guide) and the completed COREQ checklist, provided as a single supplementary document (DOCX).

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