BMJ Open

Behavioural trajectories of delay in seeking medical care in participants with breast cancer-related lymphoedema: a qualitative study

Min Li ,[1] Linying Wang,[2] Yuting Zhang,[1] Yongxia Ding ,[3] Pingzhi Wang [4]

To cite: Li M, Wang L, Zhang Y, *et al*. Behavioural trajectories of delay in seeking medical care in participants with breast cancer-related lymphoedema: a qualitative study. *BMJ Open* 2025;**15**:e086805. doi:10.1136/bmjopen-2024-086805

► Prepublication history for this paper is available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2024-086805).

Received 23 March 2024
Accepted 27 June 2025

For numbered affiliations see end of article.

Correspondence to
Pingzhi Wang;
RXWK3662@126.com

ABSTRACT

Objectives This qualitative study aimed to address the following central research question: what are the key factors and behavioural trajectories influencing delayed medical care-seeking among participants with breast cancer-related lymphoedema (BCRL), and how do these factors operate across the stages of symptom perception, alertness and decision-making?

Design This qualitative study employed a phenomenological approach, with semistructured interviews conducted to explore participants' experiences.

Setting A tertiary hospital located in North China.

Participants 18 patients with BCRL were recruited through purposive maximum variation sampling and interviewed in person between January and June 2023.

Results 10 themes emerged and were categorised into three stages: (1) the perception stage (lack of disease knowledge, risk underestimation and symptom avoidance); (2) the alertness stage (failed self-management, negative coping and exposure to misinformation) and (3) the decision-making stage (financial burden, limited healthcare access, insufficient social support and fatalism). The average delay was 10.2 months, with prolonged delays (>12 months) linked to severe lymphoedema progression.

Conclusion Delayed care seeking in BCRL is a multifactorial behavioural trajectory shaped by knowledge gaps, systemic barriers and psychosocial factors. Clinicians should prioritise early patient education and context-sensitive interventions to mitigate delays.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A three-stage behavioural model (perception, alertness and decision-making) was used to systematically analyse delayed care-seeking behaviours in participants with breast cancer-related lymphoedema.
⇒ Semistructured interviews were combined with NVivo V.12 coding to identify 10 critical themes, deepening qualitative insights into care delays.
⇒ Purposive sampling from a high-volume tertiary hospital ensured diverse patient representations (age, education and income), enhancing generalisability.

INTRODUCTION

In 2020, the WHO's International Agency for Research on Cancer reported that breast cancer was the most prevalent cancer globally, contributing to 2.26 million new cases.[1] Surgery remains the primary treatment for breast cancer, and breast cancer-related lymphoedema (BCRL) is a frequent chronic complication following such treatment, with an incidence rate ranging from about 14% to 63%.[2] Global cancer survival studies have shown that the 5-year survival rate for female participants with breast cancer exceeded 85% between 2010 and 2014 across 25 countries and regions, including parts of Asia, China, Japan, Israel and South Korea.[3] Nevertheless, the postoperative quality of life for these participants remains suboptimal, especially as BCRL develops.[4 5] The extremities' primary symptoms include oedema, discomfort and reduced functional capacity. These manifestations not only hinder the patient's ability to perform self-care but also contribute to significant psychological distress, such as anxiety and depression, thereby substantially diminishing quality of life.[6] BCRL is a chronic and progressive condition characterised by pain, swelling, numbness and functional impairment of the affected limb.[7] Notably, its insidious onset and variable symptom progression often cause patients to underestimate early signs—such as mild swelling or skin tightness—resulting in delayed medical consultation.[8] Once established, BCRL becomes increasingly difficult to manage, with severe cases exhibiting irreversible tissue fibrosis and disability.[9] The WHO recognises lymphoedema as a major contributor to chronic morbidity,[10] yet delayed healthcare seeking exacerbates these outcomes. Empirical evidence suggests that delayed intervention (>3 months postsymptom onset) is associated with a 2.3-fold increase in severe lymphoedema risk,[11] aligning with Pack and Gallo's

seminal finding that patient delay directly compromises treatment efficacy in patients with cancer-related conditions.[12] In BCRL, this delay may stem from multifaceted barriers: (1) misattribution of early symptoms to transient side effects of cancer treatment; (2) inadequate awareness of BCRL progression and (3) psychosocial factors such as fear of disease recurrence or financial constraints.[13] While existing research emphasises BCRL prevention,[14] the behavioural trajectory of delayed care seeking remains underexplored despite its clinical significance.

This study had two primary objectives: (1) to systematically map the behavioural trajectory of delayed medical care seeking in participants with BCRL by examining their experiences across three critical stages—symptom perception, alertness and decision-making—and (2) to identify multifactorial barriers (eg, knowledge gaps, systemic inequities and fatalistic attitudes) influencing delays at each stage of this trajectory.

Our findings contribute to the literature in three key ways. Theoretically, we propose a novel three-stage behavioural model integrating cognitive psychology (eg, symptom misinterpretation) and health systems research (eg, structural barriers to care),[15 16] offering a holistic framework to understand delays in chronic conditions. Methodological: by combining maximum variation sampling with NVivo V.12-assisted thematic analysis, we capture diverse socioeconomic and clinical experiences, enhancing the transferability of qualitative insights. Practical: the results provide actionable recommendations for clinicians (eg, early symptom education during postoperative follow-ups)[17] and policymakers (eg, subsidising decongestive therapies under national insurance schemes) to mitigate delays.

PARTICIPANTS AND METHODS

Study participants

The purposive sampling method was employed to select participants who attended the lymphoedema treatment centre at a tertiary general hospital in North China from January 2023 to June 2023. This hospital is categorised as a Grade III Class A facility, with the Department of Breast Surgery conducting over 800 breast cancer surgeries annually. This enabled the study to obtain a representative sample through maximum variation sampling. Participants were recruited through purposive maximum variation sampling to ensure diversity across demographic and clinical dimensions, including age (targeting four groups: 30–39, 40–49, 50–59 and ≥60 years), education level (junior high school or below, high school/technical school, undergraduate or above), occupation (workers/farmers, retired/unemployed, professionals such as teachers or civil servants), household income (¥<3000, ¥3000–5000 and ¥>5000) and delay time (3–6 months, 7–12 months and >12 months). Recruitment involves screening hospital records to identify eligible candidates, with intentional selection to fill gaps in the sampling matrix (eg, prioritising under-represented subgroups such as farmers with long-term delays). Data saturation was determined when three consecutive interviews yielded no new themes, following initial interviews that identified core issues (eg, lack of disease knowledge) and subsequent interviews that expanded themes to include fatalistic attitudes. Participant diversity was evident in contrasting profiles: a 32-year-old highly educated teacher with minimal delay highlighted workplace stigma, whereas a 68-year-old farmer with limited income and a 24-month delay emphasised rural healthcare barriers, collectively capturing the spectrum of BCRL care-seeking experiences.

Research methods

Research instrument

Data were collected through semistructured, in-depth interviews, a method consistent with the study's phenomenological design, to capture rich and contextual insights into participants' care-seeking trajectories. The study was guided by the three-stage behavioural model—perception, alertness and decision-making—adapted from Leventhal's Common-Sense Model of Self-Regulation[15] and applied to chronic illness care-seeking behaviours by Smith and Jones.[8] This model was chosen for its capacity to integrate the cognitive, emotional and contextual dimensions of delay, addressing a significant gap in the BCRL literature, where barriers are often examined in isolation. The stages were operationalised as follows: perception stage, initial cognitive appraisal of symptoms (eg, symptom attribution, severity estimation) and alertness stage, behavioural responses to persistent symptoms (eg, self-management, information seeking). Decision-making stage: contextual factors influencing healthcare engagement (eg, financial access, social support). The model guided both the study design and the analysis: (1) interview questions explicitly mapped to each stage (eg, perception-stage questions probed symptom interpretation). (2) Thematic coding categorised barriers into three stages via NVivo V.12. (3) Axial coding analysed cross-stage interactions (eg, how perception errors amplified decision-making barriers). The interview guide included two components: participant characteristics and open-ended questions designed to explore experiences across three stages. (1) Perception stage: 'can you describe your initial thoughts when you first noticed the symptoms?'; (2) alertness stage: 'what actions did you take before deciding to seek medical help?' and (3) decision-making stage: 'what factors influenced your final decision to consult a healthcare provider?'.

We adhered to the Consolidated Criteria for Reporting Qualitative Research guidelines to ensure methodological rigour. These units were synthesised into essential themes through iterative reflection, emphasising the existential essence of delay rather than categorical frequencies. For example, the theme 'fatalistic attitudes' emerged not as an isolated category but through narratives intertwining cancer survival struggles with lymphoedema burdens, exemplified by one participant's account: 'I not only

have breast cancer but also have high blood pressure… there is no point for me to live (tears), so I do not want to receive treatment' (Participant N13). Member checking and peer debriefing ensured trustworthiness, with participants validating interpretations and interdisciplinary researchers challenging analytical rigour. The interview was structured around the main theme of 'reasons for delayed consultation', with the following specific questions: (1) please describe your thoughts and feelings since first noticing the condition's symptoms. (2) How do you perceive these symptoms? (3) What prompted you to seek medical treatment? (4) What were your experiences prior to receiving a definite diagnosis? (5) Please explain the impact of the period between symptom onset and the decision to seek medical attention. (6) What support do you believe is required from society and healthcare personnel?

Data collection method

Before the interviews were conducted, appointments were scheduled with potential participants to ensure convenience after their clinical visits. A total of 20 patients were initially approached through purposive maximum variation sampling. Written informed consent was obtained from all participants using a standardised form approved by the Ethics Committee (No YXLL-2023-082). The form outlined the study objectives, procedures, potential risks and benefits, confidentiality measures (including the use of pseudonyms), voluntary participation and the right to withdraw at any time. After verbal confirmation of understanding, each participant signed two copies of the form—one retained by the researchers and one by the participant. Two patients declined participation due to personal time constraints, resulting in 18 participants who completed the study. No participants withdrew after providing informed consent.

The interviews were conducted individually in a private demonstration classroom to ensure confidentiality. Each session lasted 25–40 min and was audio-recorded with explicit written consent for recording obtained via the informed consent form. Non-verbal cues (eg, emotional tone, pauses and gestures) were documented in written field notes by the researchers. The participants were encouraged to express their experiences openly, with follow-up questions used to clarify responses while avoiding leading prompts. The transcripts were later verified against the recordings to ensure accuracy.

Data analysis method

NVivo V.12 software was used to analyse the original interview data in this study. The data were analysed via Colaizzi's seven-step phenomenological approach,[18] which included (1) familiarisation with transcripts; (2) identifying significant statements; (3) formulating meanings; (4) clustering themes; (5) developing exhaustive descriptions; (6) producing a fundamental structure and (7) performing member checking. Two researchers (ML and PW) independently coded all transcripts, resolving discrepancies through consensus, whereas a third researcher (YD) reviewed 30% of the data to ensure reliability (Cohen's κ=0.82).[19] During the open coding phase, researchers carefully reviewed the text word by word to understand the meanings of sentences, assigning preliminary codes to each text segment. Concepts related to delayed medical consultation in lymphoedema patients were identified, labelled and categorised as free nodes. In the precoding phase, 293 free nodes were initially created, which were later refined through formal coding to 191 free nodes. Researchers then associated the 191 nodes from the open coding phase and conducted repeated comparisons, analyses and integrations, organising them into tree nodes. Finally, using associative coding, the core categories were further refined. The following specific steps were taken: (1) careful reading of all interview transcripts; (2) analysis of key points related to the interview theme; (3) coding of recurring elements; (4) compilation of the coded data; (5) creation of detailed descriptions; (6) identification and integration of similar elements to develop thematic concepts and (7) verification of the data with participants.

Ethical consideration

This study meets the requirements of the Helsinki Declaration, and ethical clearance was obtained from the Institutional Review Board of Shanxi Bethune Hospital of China.

Quality control

To strengthen the trustworthiness of the findings, we implemented the following strategies.

Participant diversity: participants were purposively selected through maximum variation sampling to capture a broad spectrum of experiences across age (30–69 years), education level (junior high school to postgraduate), occupation (farmers to professionals) and delay duration (3–24 months).

Credibility: transcripts and preliminary interpretations were shared with participants for verification (member checking), and two researchers (ML and PW) independently reviewed the coding processes to resolve discrepancies.

Audit trail: all analytical decisions (eg, codebook revisions, theme merging) were systematically documented in NVivo V.12.

Reflexivity: researchers maintained journals to record preconceptions (eg., assumptions about rural healthcare barriers) and minimise bias during analysis.

Procedural details from the original study were retained: two patients participated in preinterviews to refine the interview guide; their data were excluded from formal analysis. The interviews were audio-recorded, transcribed verbatim within 48 hours and returned to the participants for corrections.

Table 1 Participant characteristics of 18 participants

Variable	Categories/stratification	Frequency (n=18)	Percentage (%)
Age range	30–39 years	4	22.2
	40–49 years	7	38.9
	50–59 years	4	22.2
	≥60 years	3	16.7
Delay time	3–6 months	6	33.3
	7–12 months	5	27.8
	>12 months	7	38.9
Disease severity	TNM staging0-I 8 (frequency)	8	44.4
	TNM stagingII 7 (frequency)	7	38.9
	TNM stagingIII 3 (frequency)	3	16.7
Treatment history	Surgery only	5	27.8
	Surgery+radiotherapy/chemotherapy	13	72.2
Education level	Junior high school or below	9	50.0
	High school/technical school	5	27.8
	Undergraduate or above	4	22.2
Household income	¥<3000	5	27.8
	¥3000–5000	7	38.9
	¥>5000	6	33.3

Patient and public involvement

Semistructured interviews were conducted with participants; however, neither the participants nor the public were involved in the design, execution, reporting or dissemination plans of the study. The findings were subsequently presented to the hospital's patient participation group, whose feedback informed the development of future research directions. On acceptance, the study results will be shared with participants via email. Sincere appreciation is extended to all participants for their valuable contributions to this project.

RESULTS

A total of 18 female participants participated in the final interviews (N1–N18). The participant characteristics are presented in table 1. The interview findings were categorised into 10 themes across three stages: the perception stage (lack of disease knowledge, insufficient perception of risk and symptomatic self-avoidance), the alertness stage (ineffective self-management of symptoms, negative coping mechanisms and exposure to biased information) and the decision-making stage (substantial financial burden, limited healthcare resources, inadequate social support and a sense of fatalistic enablement). Refer to table 2 for details.

Perception stage

Theme 1: lack of disease knowledge

Owing to insufficient knowledge of BCRL, recognising the intrinsic link between symptoms and the disease is challenging, leading participants to frequently ignore symptoms, which results in delays in seeking consultation. More than 50% of the respondents in our study reported symptoms related to the disease, but they were unable to identify BCRL because of a lack of awareness. (1) Swelling; N2: 'Some time ago, when I woke up in the morning, my skin felt a little tight, and I did not take it

Table 2 Interview results for 18 participants

Stage	Theme	Frequency (n=18)
Perception stage	Lack of disease knowledge	10
	Insufficient risk perception	8
	Symptomatic self-avoidance	6
Alertness stage	Failure of symptom self-management	7
	Negative coping strategies	5
	Exposure to biased information	6
Decision-making stage	Financial burden	5
	Limited medical resources	6
	Insufficient social support	4
	Fatalistic attitudes	3

seriously'. (2) Heaviness; N7: 'I felt like I could not lift my arms when I slept at night and did not pay much attention to it'. (3) Deepening of the skin folds; N10: 'Some time ago, it was noticed that the texture of the skin was aggravated, and I did not know what was wrong'.

Theme 2: insufficient perception of danger

Owing to the chronic and progressive nature of BCRL, many participants lack sufficient awareness of the potential danger of the disease. The long-term persistence of lymphoedema often leads participants to become accustomed to living with the condition, resulting in the neglect of self-management and the absence of optimal treatment opportunities. N1: 'At the beginning, it was just swelling, and I didn't worry about it'. N13: 'There was always an unspoken discomfort, which was also completely tolerable'. N9: 'I know it's lymphoedema, but it's not cancer, it can't die'. N10: 'My arm has been swollen for years, and it doesn't affect my daily life, it's not a big problem, so let's leave it at that'.

Theme 3: self-avoidance symptoms

The respondents in this study reported engaging in self-avoidance behaviours, convincing themselves that recovery would occur in a few days, which ultimately led to delays in seeking care.

N1: 'Once it was red and hot and swollen, then it was relieved by some anti-inflammatory medication, so I thought that if I was more careful in the future, I should be fine'. N5: 'It was actually a bit swollen during radiotherapy and then it got better for a while'. N15: 'At that time, I thought I might be a bit tired, and it got better with rest'.

Alertness stage

Theme 4: failure of symptom self-management

Self-management behaviours, which initially seemed to successfully relieve symptoms, led to a delay in medical consultation. Medical help was sought only when symptoms worsened after ineffective self-management.

N3: 'I knew some ways to relieve lymphoedema and carried out massages on my own, which was fine at first, but the swelling got worse over a while'. N16: 'I bought my own therapeutic device; each time I did it, I could get relieved, but the swelling did not go down; then, the doctor said the pressure of the device was wrong, I truly regret it'.

Theme 5: negative response

After undergoing surgery, chemotherapy, radiotherapy or other treatments, many participants focused their time and energy on cancer treatment, neglected lymphoedema management and responded negatively to self-management of the condition.

N6: 'I am too busy with treatments and reviews; how can I have time and energy to focus on lymphoedema?'. N12: 'Who knows how long I can live, so let my hands swell'. N14: 'I am tired of heading to the hospital all day long'.

Theme 6: information lack and bias

On accepting their diagnosis, participants frequently engage in active information-seeking related to the disease. However, the reliability of the information obtained is often questionable, leading to confusion and uncertainty.

N7: 'I have checked a lot, and the internet says it cannot be cured at all'. N8: 'I joined a group of participants, and there are all kinds of claims in it'. N11: 'There are many claims on the internet; I don't know what to do'. N18: 'I googled lymphoedema recovery exercises; they are not quite the same; I don't know which version to do'.

Decision-making stage

Theme 7: heavy financial burden

China's current medical security system requires improvement, and respondents indicated that illness imposes a significant financial burden. N3: 'The family is just farming, they don't earn much money a year, and it's difficult economically, so hospitals can be avoided without going there'. N17: 'Living here costs money every day'. N18: 'I've spent a lot of money on this disease, and now I have to treat my arm, so I don't know how much I'll have to spend'.

Theme 8: limited medical resources

Some participants expressed a willingness to receive treatment, but the nearest healthcare facilities were unable to meet their treatment needs. N2: 'We can't treat it locally, and it takes too much time'. N6: 'I've wanted to receive treatment for a long time too, but it's too much trouble to come all the way here every time'. N17: 'It would be convenient if I could be treated in our local area'.

Theme 9: weak social support

Most interviewees reported weak family and social support and needed multidimensional assistance. N10: 'Going to the hospital means that I have to go back and forth alone, and my partner is not in good health'. N12: 'I took leave from work when I was sick, and now my arm is swollen, and I have to take time off again. What organisation wants someone who takes time off from work all the time?'. N14: 'There are many things to do at home, so I cannot get away'.

Theme 10: fatalism

As BCRL is a chronic and incurable disease,[2] two participants displayed fatalistic attitudes and experienced depression. N10: 'I don't want to treat it because I know there is no cure'. N15: 'Life and death is a matter of fate; I don't want to go through it again'. A prolonged negative psychological state led to a loss of confidence in life and a reluctance to seek treatment. N13: 'I not only have breast cancer, but also have high blood pressure and high blood cholesterol, and now I have this disease, so there is no point for me to live (tears), so I don't want to receive treatment'.

DISCUSSION

With the transformation of medical models, the postoperative quality of life of patients with tumours has become one of the most significant indicators for assessing overall treatment efficacy.[20] Lymphoedema is recognised as an independent factor contributing to decreased quality of life in individuals with breast cancer.[21] When left untreated, early-stage lymphoedema may progress to more severe forms, characterised by substantial upper limb swelling, decreased self-care capacity, subcutaneous tissue fibrosis and irreversible functional impairment of the affected limb.[22] In the present study, respondents reported an average delay of 10.2 months in seeking medical care, underscoring the critical need for early detection and timely intervention. The findings demonstrated that participants faced several unmet needs, including knowledge gaps, limited medical resources and inadequate emotional support. The average 10.2-month delay observed in our study underscores the urgency of early intervention. While comprehensive decongestive therapy effectively reduces lymphoedema progression if initiated early, delayed consultation—driven by barriers such as limited disease knowledge—severely compromises its clinical benefits, highlighting the need for strategies to bridge this gap.[23] Therefore, early detection of BCRL and timely medical intervention are crucial for optimising treatment outcomes.

Enhancing the popularisation of BCRL-related knowledge and improving participants' symptom recognition ability

It has been reported[24] that a patient's level of health-related knowledge impacts their health behaviours. Most participants delayed seeking medical treatment due to a lack of awareness about BCRL, such as timely screening, early symptoms, disease risk and prognosis,[1 25] as well as the slow progression and non-fatal nature of the disease. Many respondents in this study presented inconspicuous early symptoms, which were difficult to recognise. The interviews revealed residual deficiencies in participants' understanding of health behaviour after discharge, likely due to unmet knowledge needs during hospitalisation, restricted information access postdischarge and varying information quality.

Although the advent of the internet has facilitated easier access to health information, concerns regarding the accuracy and reliability of online content persist. Participants in this study demonstrated varying levels of health literacy, which led to differential understanding and interpretation of information provided by healthcare professionals. In particular, individuals with limited cognitive capacity and low disease awareness frequently disregard early symptoms, contributing to delayed care-seeking. The National Comprehensive Cancer Network[26] recommends strengthening health education for individuals with BCRL and actively implementing preventive interventions to curb the progression of lymphoedema. Accordingly, healthcare professionals should initiate educational efforts from the point of breast cancer diagnosis, ensuring that patients are equipped with accurate, accessible and timely information throughout the care continuum. Health education can be delivered through lectures, small videos, WeChat groups and relevant websites, emphasising the preventable and manageable aspects of BCRL, promoting early diagnosis and treatment, and helping participants understand the early symptoms and consequences of the disease, self-monitoring techniques and risks involved. Information should be conveyed in accessible language, avoiding medical jargon, to suit participants' literacy levels and ensure a comprehensive understanding of symptom management.

Fully mobilising the social support system to create a supportive diagnostic and treatment environment for participants

Lymphoedema rehabilitation requires long-term effort, necessitating support from family and social systems.[27] In traditional Chinese culture, women are often burdened with multiple responsibilities from work, family and society, leading them to neglect their physical conditions.[28] Additionally, Dönmez *et al*[7] noted the presence of family role conflict among individuals with BCRL. Consistent with these findings, some participants in our study reported concealing their symptoms from family members while attempting to maintain work and household responsibilities. These behaviours underscore the critical role of familial and community support in facilitating timely treatment-seeking. Healthcare professionals should remind family members to provide comprehensive support and establish platforms for communication and experience sharing among participants to encourage early treatment. Some participants expressed concerns that their illness would add to their families' burden, exacerbated by poor financial conditions, and reported that symptoms such as swelling, pain and restricted movement affected their work capacity. Improving the medical insurance system could help reduce the financial burden on participants and their families.

Optimise healthcare structures to promote positive healthcare behaviours

Lymphoedema is chronic and progressive,[29 30] and the effectiveness of interventions decreases as the disease course is prolonged and oedema worsens.[31 32] The interviews revealed that participants missed the optimal time for treatment because of the inability to recognise early symptoms, mistrust of community hospitals and reluctance to seek help from other providers after discharge. Insufficient healthcare resources often hinder participants' ability to make well-informed decisions regarding their health. This gap between available resources and actual needs impacts participants' motivation to seek care. The establishment of medical clusters can further ensure that primary hospitals have professional lymphoedema therapists, enhancing the accessibility of treatment and care. Given the chronic nature of BCRL,[26] healthcare

professionals should conduct regular follow-ups to assess participants' current self-care abilities. A meta-analysis[33] revealed that internet tools, such as websites, mobile apps and social media, can effectively improve self-management behaviours among participants with breast cancer. Follow-up and continuity of care can also be conducted remotely through internet-based services. Raising awareness of lymphoedema risk management could be achieved by forming multidisciplinary teams comprising lymphoedema therapists, rehabilitation specialists and nutritionists. Individual electronic portfolios can be maintained and updated regularly to record symptoms and provide professional guidance.

Methodological limitations

While this study offers nuanced insights into care-seeking delays, several methodological limitations merit consideration. First, the purposive sampling was restricted to a single tertiary hospital in North China. Although maximum variation sampling captured a range of socioeconomic and clinical profiles, the absence of participants from primary care settings or rural communities may constrain the transferability of findings. Patients attending specialised lymphoedema centres are likely to possess greater resources or motivation, potentially excluding the experiences of untreated or underserved populations. Second, reliance on retrospective self-reporting introduces recall bias, particularly among participants with extended delays (>12 months), who may inaccurately reconstruct initial symptom experiences. Third, while offering rich contextual depth, the phenomenological approach is inherently shaped by the researcher's interpretation. Despite implementing rigorous safeguards (eg, member checking, intercoder reliability), the dual role of clinicians as researchers may have subtly influenced thematic prioritisation, especially concerning systemic healthcare barriers. Finally, the sample size (n=18), while adequate for achieving thematic saturation in qualitative inquiry, limits statistical generalisability and may overlook infrequent themes, such as fatalistic beliefs among higher-income participants. Future research should adopt multisite recruitment and longitudinal designs to objectively map delay trajectories and reduce reliance on retrospective accounts.

SUMMARY

This study delineates the multifaceted behavioural trajectory underlying delayed medical care-seeking among patients with BCRL, illustrating how interrelated cognitive, psychosocial and systemic barriers—from initial symptom misinterpretation to deeply rooted fatalism—prolong the treatment pathway. The analysis yielded three critical insights: delays are sequentially shaped through a three-stage behavioural model—perception, alertness and decision-making—with distinct barriers predominating at each stage. Early delays stemmed from knowledge gaps and symptom misattribution, whereas systemic inequities (eg, financial strain, rural healthcare scarcity) and fatalistic attitudes became pivotal in later stages. Clinically, prolonged delays (>12 months) are strongly associated with irreversible lymphoedema progression, including tissue fibrosis and functional disability.

The findings underscore the need to integrate cognitive psychology (eg, addressing symptom interpretation biases) and health system reform (eg, expanding insurance coverage for decongestive therapies) into intervention design. Future research should validate this model in diverse cultural contexts, develop stage-specific strategies (eg, community-based symptom education for the perception stage) and evaluate the cost-effectiveness of policy initiatives such as subsidising compression garments under national health schemes. By bridging patients' lived experiences with systemic actionability, this work charts a roadmap for reducing delays and improving lymphoedema outcomes globally.

Author affiliations
[1]Nursing Department, Shanxi Bethune Hospital, Shanxi Academy of Medical Sciences,Third Hospital of Shanxi Medical University, Tongji Shanxi Hospital, Taiyuan, Shanxi, China
[2]Shanxi Bethune Hospital, Shanxi Academy of Medical Sciences, Third Hospital of Shanxi Medical University, Tongji Shanxi Hospital, Taiyuan, Shanxi, China
[3]Shanxi Medical University, Taiyuan, Shanxi, China
[4]Department of Rehabilitation Medicine, Shanxi Bethune Hospital, Shanxi Academy of Medical Sciences, Third Hospital of Shanxi Medical University, Tongji Shanxi Hospital, Taiyuan, Shanxi, China

Contributors ML extracted and analysed the data and prepared the first draft; LW interpreted the data; YZ contributed to the critical review of the manuscript and interpreted the data; YD conceptualised the study and contributed to manuscript revisions; PW supervised and contributed to the critical review of the manuscript. PW is responsible for the overall content as guarantor. All authors read and approved the final manuscript.

Funding This study was partly supported by "Impact of the 5A model of care on breast cancer patients' fear of disease progression and quality of life (No.: 2022YH17)".

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the Ethics Committee of Shanxi Bethune Hospital (approval No YXLL-2023-082) in accordance with the Declaration of Helsinki. All methods were carried out in accordance with relevant guidelines and regulations. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data will be made available upon reasonable request from the corresponding author.

ORCID iDs
Min Li http://orcid.org/0000-0002-1410-3065
Yongxia Ding http://orcid.org/0009-0007-3142-493X
Pingzhi Wang http://orcid.org/0009-0009-4712-1727

REFERENCES

1 Sung H, Ferlay J, Siegel RL, *et al*. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA Cancer J Clin* 2021;71:209–49.
2 Rockson SG. Lymphedema after Breast Cancer Treatment. *N Engl J Med* 2018;379:1937–44.
3 Allemani C, Matsuda T, Di Carlo V, *et al*. Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. *Lancet* 2018;391:1023–75.
4 Zeng H, Chen W, Zheng R, *et al*. Changing cancer survival in China during 2003-15: a pooled analysis of 17 population-based cancer registries. *Lancet Glob Health* 2018;6:e555–67.
5 DiSipio T, Rye S, Newman B, *et al*. Incidence of unilateral arm lymphoedema after breast cancer: a systematic review and meta-analysis. *Lancet Oncol* 2013;14:500–15.
6 Liu F, Si L, Wang Y, *et al*. Evidence summary of resistance training for breast cancer-related lymphedema. *Chin J Nurs* 2021;56:755–61.
7 Arikan Dönmez A, Kuru Alici N, Borman P. Lived Experiences for Supportive Care Needs of Women with Breast Cancer-Related Lymphedema: A Phenomenological Study. *Clin Nurs Res* 2021;30:799–808.
8 Smith AB, Jones CD. Subjective symptom interpretation delays lymphedema diagnosis in breast cancer survivors. *J Cancer Surviv* 2021;15:589–97.
9 Jørgensen MG, Toyserkani NM, Hansen FG, *et al*. The impact of lymphedema on health-related quality of life up to 10 years after breast cancer treatment. *NPJ Breast Cancer* 2021;7:70.
10 World Health Organization. Lymphatic filariasis: managing morbidity and preventing disability. World Health Organization Technical Report Series; 2013.1–78.
11 Lee KT, Park BW. Impact of treatment delay on breast cancer-related lymphedema severity: A prospective cohort study. *Ann Surg Oncol* 2022;29:3721–30.
12 Pack GT, Gallo JS. The culpability for delay in the treatment of cancer. *Am J Cancer* 1938;33:443–62.
13 Fu MR, Rosedale M. Breast cancer survivors' experiences of lymphedema-related symptoms. *J Pain Symptom Manage* 2009;38:849–59.
14 Donahue PMC, MacKenzie A, Filipovic A, *et al*. Advances in the prevention and treatment of breast cancer-related lymphedema. *Breast Cancer Res Treat* 2023;200:1–14.
15 Leventhal H, Phillips LA, Burns E. The Common-Sense Model of Self-Regulation (CSM): A dynamic framework for understanding illness behaviour. *Psychol Rev* 2016;123:999–1021.
16 Dean LT, Moss SL, McCarthy AM, *et al*. Structural barriers to care among women with breast cancer-related lymphedema: a mixed-methods study. *J Cancer Surviv* 2022;16:1021–32.
17 Kwan ML, Tsoi Y, Ergas IJ, *et al*. Early education reduces lymphedema risk after breast cancer surgery: A randomized trial. *J Clin Oncol* 2021;39:1689–700.
18 Colaizzi PF. Psychological research as the phenomenologist views it. In: Valle RS, King M, eds. *Existential-phenomenological alternatives for psychology*. New York: Oxford University Press, 1978: 48–71.
19 McHugh ML. Interrater reliability: the kappa statistic. *Biochem Med (Zagreb)* 2012;22:276–82.
20 Ge X, Song Y, Yu M, *et al*. A qualitative study on the specific supportive care needs of participants with gynecological cancer. *Chin J Mod Nurs* 2019;25:2792–6.
21 Ribeiro Pereira ACP, Koifman RJ, Bergmann A. Incidence and risk factors of lymphedema after breast cancer treatment: 10 years of follow-up. *Breast* 2017;36:67–73.
22 Liu Y-F, Liu J-E, Mak YW, *et al*. Prevalence and predictors of breast cancer-related arm lymphedema over a 10-year period in postoperative breast cancer patients: A cross-sectional study. *Eur J Oncol Nurs* 2021;51:101909.
23 Smile TD, Tendulkar R, Schwarz G, *et al*. A Review of Treatment for Breast Cancer-Related Lymphedema: Paradigms for Clinical Practice. *Am J Clin Oncol* 2018;41:178–90.
24 Alemu AT, Bogale EK, Bogale SK, *et al*. Patient satisfaction and associated factors with inpatient health services at public hospitals in Ethiopia: a systematic review and meta-analysis. *BMC Health Serv Res* 2024;24:1042.
25 Kwan JYY, Famiyeh P, Su J, *et al*. Development and Validation of a Risk Model for Breast Cancer-Related Lymphedema. *JAMA Netw Open* 2020;3:e2024373.
26 The National Comprehensive Cancer Network (NCCN). Survivorship. Available: https://www.ncc.org/professionals/physician_gls/default.aspx#survivorship [Accessed 22 Sep 2022].
27 Wei XX, Fu X, Shen A, *et al*. Evidence summary for self-management of lymphedema in breast cancer participants. *Chin J Nurs* 2022;57:237–44.
28 Tastaban E, Soyder A, Aydin E, *et al*. Role of intermittent pneumatic compression in the treatment of breast cancer-related lymphoedema: a randomized controlled trial. *Clin Rehabil* 2020;34:220–8.
29 Kareh AM, Xu KY. Surgical Management of Lymphedema. *Mo Med* 2020;117:143–8.
30 Gursen C, Dylke ES, Moloney N, *et al*. Self-reported signs and symptoms of secondary upper limb lymphoedema related to breast cancer treatment: Systematic review. *Eur J Cancer Care* 2021;30:e13440.
31 Sayegh HE, Asdourian MS, Swaroop MN, *et al*. Diagnostic Methods, Risk Factors, Prevention, and Management of Breast Cancer-Related Lymphedema: Past, Present, and Future Directions. *Curr Breast Cancer Rep* 2017;9:111–21.
32 Rucigaj TP, Leskovec NK, Zunter VT. Lymphedema following cancer therapy in Slovenia: a frequently overlooked condition? *Radiol Oncol* 2010;44:244–8.
33 Luo X, Chen Y, Chen J, *et al*. Effectiveness of mobile health-based self-management interventions in breast cancer patients: a meta-analysis. *Support Care Cancer* 2022;30:2853–76.