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Trajectories of lymphedema risk perception and their predictors in postoperative breast cancer survivors

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Abstract

Background Risk perception is considered an important component of patients' self-management in breast cancer-related lymphedema (BCRL). However, existing evidence is largely cross-sectional and provides limited understanding of how risk perception evolves over time in the early postoperative period.

Objective This study aimed to describe the level of lymphedema risk perception at discharge and to explore its change trajectories during the first 6 months after surgery in patients with breast cancer.

Methods Participants were recruited from two tertiary grade A hospitals in China and completed a baseline survey (questionnaires on demographic and clinical characteristics, lymphedema risk perception, health literacy, communication patterns, and perceived social support) and follow-up assessments (Lymphedema Risk Perception Questionnaire) at the 1st, 3rd, and 6th months postoperatively.

Results Among 225 patients completing baseline, 185 (82.3%) completed the 6-month follow-up. Risk perception showed moderate overall levels with an initial rise followed by decline. Three distinct trajectories emerged: high–gradually declining group, moderate–peaked group, and low–peaked group. Key predictors included education, health education exposure, treatment type, surgery, disease stage, health literacy, communication patterns, and social support.

Conclusion This study identified the change trajectories and latent classes of lymphedema risk perception within 6 months after surgery in breast cancer patients and revealed the predictive effects of demographic, clinical, and psychosocial factors on these trajectories.

Implications for cancer survivors Breast cancer survivors should tailor their self-management strategies based on their BCRL risk perception trajectories. Those in the low–peaked group are advised to actively participate in lymphedema-related health education and enhance health literacy to improve risk awareness timely. The moderate–peaked group needs to reinforce knowledge and self-monitoring to maintain stable perception. The high–gradually declining group needs to maintain appropriate vigilance through regular self-monitoring and avoid risk perception fatigue. These suggestions are intended to provide risk perception trajectory-based stratified self-management support for patients, while further research is needed to determine their impact on long-term clinical outcomes.

Keywords Breast cancer · Lymphedema · Risk perception · Trajectory · Latent class growth analysis

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Introduction

Breast cancer-related lymphedema (BCRL) is a common and serious complication following breast cancer surgery. It primarily presents with symptoms such as limb swelling, numbness, pain, and functional impairment in the affected arm. Moreover, it can lead to psychological issues, including feelings of inferiority and stigma [1]. These manifestations severely affect patients' quality of life [2]. BCRL incidence increases over time. However, due to variations in diagnosis timing, tools, and follow-up duration, its reported cumulative incidence ranges from 13.5% to 41.1% [3]. BCRL is progressive and irreversible [4]. Once it occurs, patients require lifelong care and attention [5]. It affects patients' physical and mental health [6]. Studies have shown that BCRL can occur as early as 1 month after surgery, and its incidence gradually increases within 2 years after surgery, with a more rapid growth rate in the first year, accounting for approximately 75% of the total incidence [7]. Therefore, the early detection and prevention of BCRL are of critical importance for the rehabilitation of postoperative breast cancer patients. The Guidelines for the Diagnosis and Treatment of Upper Limb Lymphedema after Breast Cancer Surgery in China also further emphasize that the cornerstone of BCRL management is patient education and early preventive intervention [8].

An individual's response to health risks is based on their risk perception. Studies show that risk perception levels closely relate to health behaviors and coping strategies. Moderate risk perception can motivate positive preventive behaviors and strengthen health beliefs [9]. Although arm circumference measurement provides an objective assessment in clinical practice [10], patients' cognitive capacity and symptom awareness vary considerably. Consequently, clinical management still relies heavily on patients' subjective perception, which may result in missed opportunities for optimal early intervention. International guidelines for BCRL prevention emphasize that enhancing patients' risk perception is essential to preventing the onset and progression of BCRL. Recognizing and strengthening risk perception is therefore critical to reducing the incidence and further deterioration of BCRL [11] and offers a promising direction for intervention development. Accordingly, improving risk perception among patients with breast cancer constitutes a pivotal step toward promoting adherence to preventive behaviors and facilitating timely intervention.

However, risk perception is not static; it can change dynamically over time. When facing health threats like BCRL, individuals continuously adjust their illness perceptions based on physical symptoms, personal experiences, and information from healthcare interactions and social environments. This dynamic process is influenced by both internal sensations and external information, fluctuating throughout the disease course [12]. Investigating the dynamic changes and potential heterogeneity in BCRL risk perception, along with identifying factors influencing different trajectories, is crucial for understanding its evolution mechanisms and providing timely, precise interventions for patients.

This study integrates the Chronic Illness Trajectory Framework (CITF) and the Triadic Theory of Influence (TTI) as its theoretical foundation. The CITF provides the basis for investigating the dynamic trajectories of BCRL risk perception during postoperative recovery [13, 14]. The TTI offers a multidimensional analytical framework, examining the formation of risk perception across personal, interpersonal, and environmental levels [15]. Based on the Triple Theory of Influence (TTI), this study selected representative variables from the individual, interpersonal, and social environmental levels to explore the influencing factors of lymphedema risk perception in patients after breast cancer surgery. At the individual level, health literacy is an important foundation for patients to understand lymphedema risk. Previous studies [16, 17] have shown that knowledge level and information comprehension ability significantly influence disease risk perception and engagement in preventive behaviors. In addition, patients' illness perceptions and emotional distress have been identified as important predictors of risk perception [18]. At the interpersonal level, physician–patient (nurse–patient) communication serves as the primary channel through which patients obtain information regarding lymphedema risk. Inadequate or ineffective communication may attenuate patients' risk perception, whereas most patients prefer to receive relevant information directly from healthcare professionals through interpersonal communication [19]. Studies by Wang et al. [20] and Cal et al. [21] have demonstrated that family support and peer communication exert positive effects on lymphedema risk management. This theoretical framework provides a useful lens for explaining the heterogeneity observed in risk perception trajectories. Accordingly, guided by the Triple Theory of Influence, the present study investigates the associations among health literacy, physician–patient (nurse–patient) communication patterns, social support, and lymphedema risk perception.

Current research on illness risk perception primarily focuses on chronic conditions such as cardiovascular diseases and diabetes [22–24], while studies specifically addressing risk perception of breast cancer-related lymphedema remain limited. A qualitative research revealed that patients' risk perception of lymphedema mainly manifests as limited knowledge, tendency to avoid confronting its possibility, and underestimation of its severity [25]. Based on these findings, researchers have developed a tailored assessment questionnaire for evaluating lymphedema risk perception in women with breast cancer [26]. A study by Luo et al. [27] demonstrated that illness perception can predict lymphedema risk-management behaviors in breast

cancer survivors within 6 months after surgery. Currently, there is a lack of widely validated, specialized assessment tools for the specific construct of risk perception related to breast cancer-related lymphedema.

Few studies have examined the factors influencing patients' perceptions of BCRL risk. Moreover, patients' psychological states change dynamically across different disease stages. Chen et al. [28] investigated the overall level and changing trends of BCRL risk perception in breast cancer patients during the first 6 months postoperative. The degree of perception and change trajectories may vary among individuals due to factors such as personal characteristics, psychological resilience, and social support.

Lymphedema risk perception demonstrates dynamic changes and may be influenced by demographic, clinical, and psychosocial factors. Previous studies have been limited to cross-sectional designs, making it challenging to reveal individual dynamic changes in BCRL risk perception. Furthermore, there remains insufficient research on whether heterogeneity exists in the developmental trajectories of patients' lymphedema risk perception and the underlying influencing factors. Therefore, this study aims to (a) assess the status of BCRL risk perception in postoperative breast cancer patients before discharge; (b) analyze their risk perception levels, dynamic change trends, and trajectory heterogeneity across different postoperative rehabilitation stages; and (c) identify key factors influencing risk perception trajectories.

Methods

Study design and participants

This study adopted a prospective, longitudinal descriptive design to systematically observe changes over time. Using a convenience sampling method, breast cancer patients who underwent surgery were recruited between February 2024 and June 2024 from the breast surgery departments of two tertiary grade A hospitals in Xi'an, China. The inclusion criteria were as follows: confirmed diagnosis of breast cancer; age 18 years or older; undergoing breast cancer surgery for the first time; possessing basic communication and comprehension abilities; and being aware of their diagnosis. Patients were excluded if they had psychiatric disorders or cognitive impairment, other malignant tumors, or had experienced major stressful events within the last 3 months.

Sample size calculation

Sample size was determined based on two considerations. First, following Kendall's principle [29], which recommends 5–10 subjects per independent variable, a sample of 105–210 was required for the 21 variables. To account for an anticipated 20% attrition rate in this longitudinal design, this initial estimate was divided by 0.8 (i.e., to ensure an 80% retention rate), resulting in a target sample size range of 131–262. Second, an a priori power calculation for a single-sample repeated-measures design (with four measurements, an average correlation $\rho = 0.05$, an effect size $f = 0.14$, $\alpha = 0.05$, and 80% power) indicated a minimum of 142 participants. To conservatively meet both requirements, a total of 225 participants were enrolled at baseline.

Data collection

A total of 225 eligible women were screened and completed the baseline survey (T0) before discharge, including questionnaires on demographic characteristics, lymphedema risk perception, health literacy, communication patterns, and perceived social support. Follow-up surveys were conducted at 1, 3, and 6 months postoperatively (T1, T2, T3) when participants returned to the hospital for review. For women unable to return to the hospital, investigators collected data through telephone follow-ups.

Measures

Demographic and clinical characteristics

Demographic and clinical data, including age, body mass index, educational attainment, marital status, residential address, income, history of health education regarding lymphedema, comorbidities, treatment modalities, surgical approach, disease stage, tumor location, and type of surgical incision, were collected through patients' self-reports and researchers' access to the medical record system.

Risk perception

This study used the revised Brief Lymphedema Risk Perception Questionnaire to assess patients' illness risk perception. The questionnaire was adapted by Shen Aomei's research group [30] in 2023 from the Chinese version of the Brief Illness Perception Questionnaire translated by Lin et al. [31] with modifications specific to breast cancer-related lymphedema characteristics and psychometric evaluation. The 9-item questionnaire consists of two dimensions from the first 8 items: cognitive representation and emotional representation. Items 1–8 use a 0–10 scoring system without reverse scoring, with higher scores indicating stronger cognitive or emotional representations. Item 9 is an open-ended question exploring three potential risk factors for lymphedema from patients' perspectives, allowing for qualitative analysis. In this study, the scale's Cronbach's α was 0.856.

Health literacy

The Health Literacy Management Scale (HeLMS) was used in this study to assess patients' health literacy levels. Originally developed by Jordan et al. [32], the scale evaluates health literacy from the patient's perspective. The Chinese version, translated and adapted by Sun Haolin [33], contains 24 items across four dimensions: information acquisition ability (9 items), communication and interaction ability (9 items), willingness to improve health (4 items), and economic support willingness (2 items). Using a 5-point Likert scale with a maximum score of 120, higher scores indicate better health literacy. The HeLMS demonstrates high reliability, with Cronbach's α coefficients for the four dimensions ranging from 0.885 to 0.925, indicating good internal consistency. The scale comprehensively assesses patients' abilities in health information processing, communication, and health management, helping healthcare providers understand patients' health literacy. In this study, the scale's Cronbach's α was 0.725.

Communication patterns

The Patient Communication Patterns Scale (PCPS) was used in this study to assess patients' communication patterns during treatment decision-making. Originally developed by Ilan et al. [34] in 2016, the Chinese version was translated by Xiao Lin et al. [35] to evaluate communication patterns among Chinese cancer patients during treatment decision-making. The 11-item scale comprises two dimensions: disease and treatment information communication and emotional expression. The original scale demonstrated excellent reliability with a Cronbach's α of 0.938 for the total scale, and 0.944 and 0.890 for the two subscales, respectively. The scale uses a 1 to 6 scoring system, with total scores ranging from 11 to 66. In this study, the scale's Cronbach's α was 0.830.

Social support

The Perceived Social Support Scale (PSSS) was used in this study to evaluate patients' social support levels. Originally developed by Zimet et al. [36] in 1987, the PSSS measures an individual's subjective perception of social support. The scale has been widely used in diverse populations including general communities, patient groups, adolescents, and elderly individuals. The Chinese version, translated and adapted by Zhang Fan [37], has been applied in studies of social support among hospitalized patients in China. The 12-item scale comprises three dimensions: family support, friend support, and significant other support. The overall scale demonstrates good reliability with a Cronbach's α of 0.840, while the subscales show α coefficients of 0.818, 0.820, and 0.813, respectively. The scale uses a 1 to 7 scoring system, with total scores ranging from 12 to 84. Higher scores indicate a greater degree of perceived social support. In this study, the scale demonstrated a Cronbach's α of 0.846.

Ethical considerations

Before the study, all participants were informed of the research purpose, content, and the confidentiality of privacy-related information. Then, verbal informed consent was obtained from all subjects. This study was approved by the hospital's research ethics committee (XJTU1AF2024LLSYY-088).

Data analysis

All data were analyzed using IBM SPSS Statistics 25.0 for Windows (SPSS Inc, Chicago, Illinois) and Mplus 8.3 (Muthén & Muthén, Los Angeles, California). For continuous data, if the data satisfied normal distributions, the mean and SD were used for descriptive statistics; otherwise, the median and interquartile range were selected. Categorical data were shown as frequencies (n) and percentages (%). In univariate analysis, continuous data meeting assumptions of normality and homogeneity of variance were analyzed using independent samples *t*-tests or ANOVA to compare group differences; non-parametric tests were used when these assumptions were violated. For multivariate analysis, multicollinearity diagnostics were performed prior to multiple linear regression analysis, with variance inflation factor (VIF) values below 5 indicating no significant multicollinearity. Repeated measures ANOVA was employed to examine differences in lymphedema risk perception scores across time points. Latent growth curve modeling (LGCM) was used to describe the overall developmental trajectory of lymphedema risk perception in postoperative breast cancer patients from T0 to T3. Model evaluation indices included the comparative fit index (CFI), Tucker-Lewis index (TLI), standardized root mean square residual (SRMR), Akaike information criterion (AIC), Bayesian information criterion (BIC), and sample size-adjusted BIC (aBIC). Better model fit was indicated by CFI > 0.90, SRMR < 0.08, and smaller values of AIC and BIC. Latent class growth analysis (LCGA) was conducted to identify heterogeneous trajectories of lymphedema risk perception in postoperative breast cancer patients. Differences in demographic and disease-related characteristics across trajectory classes were examined using χ^2 tests for categorical variables. For continuous variables meeting normality assumptions, one-way

ANOVA was applied; otherwise, non-parametric tests were used. Variables showing statistical significance in univariate analyses were subsequently included in a multivariate logistic regression model to identify factors associated with heterogeneous trajectories of lymphedema risk perception. All tests were two-tailed, and $P < 0.05$ was considered statistically significant.

Results

Participant flow

The flow of participants through each stage of the study is presented in Fig. 1. Among the 225 patients who completed the baseline survey (T0), 217 completed the 1-month follow-up (T1), 205 completed the 3-month follow-up (T2), and 185 completed the 6-month follow-up (T3), resulting in an overall attrition rate of 17.7%.

Sample characteristics

A total of 225 patients completed the baseline survey before discharge. Patient characteristics revealed a mean age of 51.34 ± 11.712 years, with the majority being married (94.2%), urban residents (68.8%), and retired (51.1%). Medical payments were primarily covered by health insurance (98.7%). Regarding disease profiles, 48.9% were diagnosed with stage II breast cancer. The distribution across the three surgical approaches was balanced, with most tumors located in the upper outer quadrant (60.5%) and transverse incisions being the predominant surgical technique (88.9%). Additionally, 44% of patients received combination therapy. During the follow-up period, 40 participants were lost to follow-up, with no significant differences observed in baseline characteristics between study completers and non-completers ($P > 0.05$). See Table 1 for more demographic characteristics.

Analysis of factors influencing BCRL risk perception before discharge

We assessed relevant indicators in postoperative breast cancer patients before discharge. The total BCRL risk perception scores were normally distributed, with a mean score of 42.13 ± 13.829 points. The emotional representation dimension score was higher than the cognitive representation dimension score. Scores for health literacy, patient communication patterns, and social support all showed non-normal distributions, with median scores of 92, 45, and 61 points, respectively. Detailed scores for specific dimensions of each scale are provided in Supplementary Table 1.

Multiple linear regression analysis was performed with BCRL risk perception as the dependent variable and statistically significant variables from the general information as independent variables, including education level, monthly family income per capita, receipt of health education, treatment modality, surgical approach, health literacy, patient communication patterns, and perceived social support (details in Supplementary Table 2). Multicollinearity diagnostics showed tolerance values ranging from 0.588

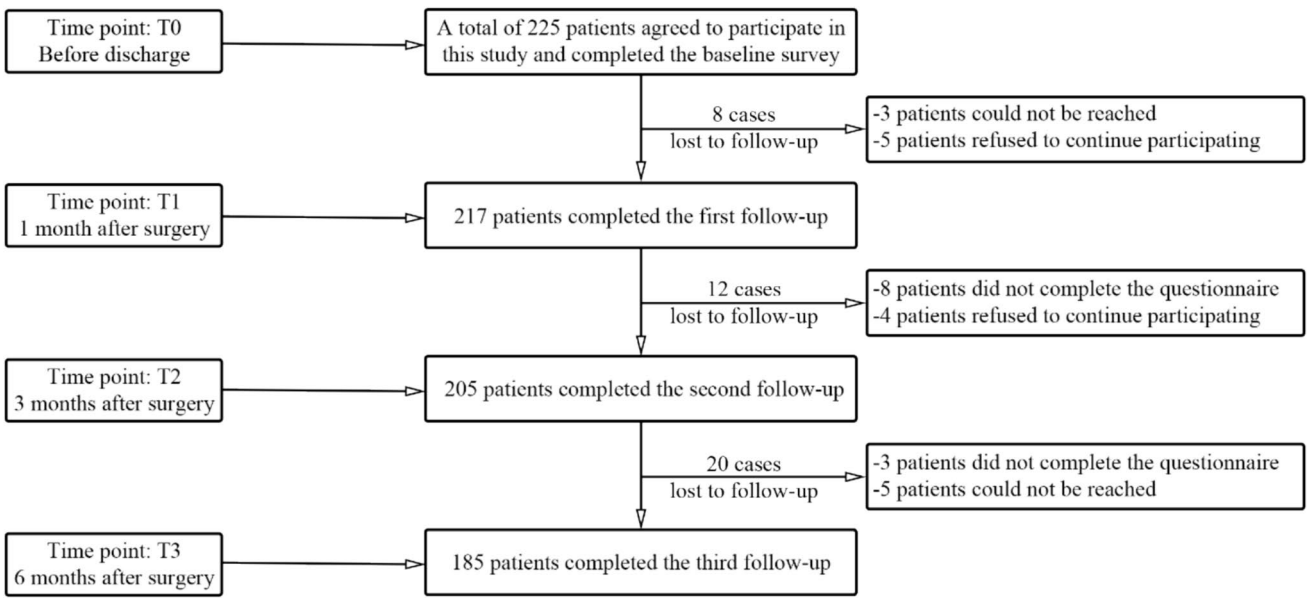

Fig. 1 Flowchart of participant recruitment and follow-up

Table 1 Demographic and disease-related data of postoperative breast cancer patients

Variables	Baseline ($N=225$)	Completed ($N=185$)	Lost ($n=40$)	Comparison	
	n (%)	*n* (%)	*n* (%)	χ^2	*P*
Age, y					
< 40	40 (17.8)	36 (19.5)	4 (10)	2.242	0.326
40 ~ 60	133 (59.1)	106 (57.3)	27 (67.5)		
> 60	52 (23.1)	43 (23.2)	9 (22.5)		
BMI, kg/m^2					
< 18.5	15 (6.7)	13 (7)	2 (5)	4.277	0.118[a]
18.5 ~ 23.9	119 (52.9)	92 (49.7)	27 (67.5)		
≥ 24	91 (40.4)	80 (43.3)	11 (27.5)		
Educational level					
Primary school or below	38 (16.9)	34 (18.4)	4 (10)	2.67	0.263
Secondary/high school	102 (45.3)	85 (45.9)	17 (42.5)		
College or above	85 (37.8)	66 (35.7)	19 (47.5)		
Marital status					
Married	212 (94.2)	175 (94.6)	37 (92.5)	0.02	0.888
Unmarried	13 (5.8)	10 (5.4)	3 (7.5)		
Residential address					
City	157 (69.8)	128 (69.2)	29 (72.5)	0.171	0.679
Country	68 (30.2)	57 (30.8)	11 (27.5)		
Employment status					
Employed	58 (25.8)	47 (25.4)	11 (27.5)	1.761	0.415
Unemployed	52 (23.1)	40 (21.6)	12 (30)		
Retired	115 (51.1)	98 (53)	17 (42.5)		
Per capita monthly income, yuan					
< 1000	67 (29.8)	59 (31.8)	8 (20)	2.873	0.238
1000 ~ 5000	117 (52.0)	95 (51.4)	22 (55)		
> 5000	41 (18.2)	31 (16.8)	10 (25)		
Payment method					
Employee medical insurance	119 (52.9)	97 (52.4)	22 (55)	0.016	0.901[b]
Resident basic medical insurance	103 (45.8)	86 (46.5)	17 (42.5)		
Out-of-pocket	3 (1.3)	2 (1.1)	1 (2.5)		
Primary caregiver					
Family member(s)	217 (96.4)	178 (96.2)	39 (97.5)	0.158	0.691[a]
Self	8 (3.6)	7 (3.8)	1 (2.5)		
Family relationship quality					
Good	208 (92.4)	170 (91.9)	38 (95)	0.119	0.730[a]
Fair/poor	17 (7.6)	15 (8.1)	2 (5)		
Health education					
Yes	127 (56.4)	108 (58.4)	19 (47.5)	1.583	0.208
No	98 (43.6)	77 (41.6)	21 (52.5)		
Comorbidities					
No	168 (74.7)	139 (75.1)	29 (72.5)	0.121	0.728
Yes	57 (25.3)	46 (24.9)	11 (27.5)		
Treatment modality					
Surgery	126 (56)	103 (55.6)	23 (57.5)	0.536	0.765
Endocrine/targeted therapy + surgery	39 (17.3)	31 (16.8)	8 (20)		
Chemotherapy + surgery	60 (26.7)	51 (27.6)	9 (22.5)		
Breast surgery					
MRM	75 (33.3)	64 (34.6)	11 (27.5)	2.069	0.355

Table 1 (continued)

Variables	Baseline ($N=225$)	Completed ($N=185$)	Lost ($n=40$)	Comparison	
	n (%)	*n* (%)	*n* (%)	χ^2	*P*
BCS/mastectomy + ALND	76 (33.8)	64 (34.6)	12 (30)		
BCS/mastectomy + SLNB	74 (32.9)	57 (30.8)	17 (42.5)		
Tumor stages					
0	24 (10.7)	22 (11.9)	2 (5)	5.075	0.166[b]
I	65 (28.9)	50 (27)	15 (37.5)		
II	110 (48.9)	94 (50.8)	16 (40)		
III/IV	26 (11.5)	19 (10.3)	7 (17.5)		
Tumor location					
UOQ	136 (60.5)	110 (59.5)	26 (65)	2.891	0.409[a]
LOQ	39 (17.3)	32 (17.2)	7 (17.5)		
UIQ	34 (15.1)	31 (16.8)	3 (7.5)		
LIQ	16 (7.1)	12 (6.5)	4 (10)		
Incision type					
Horizontal Incision	200 (88.9)	165 (89.2)	35 (87.5)	0.001	0.975[a]
Non-horizontal incision	25 (11.1)	20 (10.8)	5 (12.5)		

BMI body mass index, *MRM* modified radical mastectomy, *BCS* Breast-conserving surgery, *ALND* axillary lymph node dissection, *SLNB* sentinel lymph node biopsy, *UOQ* Upper outer quadrant, *LOQ* lower outer quadrant, *UIQ* upper inner quadrant, *LIQ* lower inner quadrant

[a]Continuity-corrected χ^2 test

[b]Fisher's exact test

Table 2 Multiple linear regression of BCRL risk perception at discharge

Variable	Coefficient	Standard error	Standardized coefficient	t	*P*
Constant	8.908	7.461	-	1.194	0.234
Educational level	2.942	1.213	0.151	2.425	0.016
Household income	0.364	1.139	0.018	0.320	0.749
Health education	−5.396	1.517	−0.194	3.557	< 0.001
Treatment modality	2.478	0.985	0.137	2.516	0.013
Surgical procedure	−2.917	0.989	−0.172	−2.949	0.004
Health literacy	0.138	0.062	0.144	2.222	0.027
Patient communication pattern	0.245	0.102	0.162	2.389	0.018
Perceived social support	0.158	0.08	0.115	1.980	0.039

$R^2=0.416$, adjusted $R^2=0.394$, $F=19.203$, $P<0.001$

to 0.905 and VIF values from 1.105 to 1.701, indicating no multicollinearity among variables. The multivariate analysis revealed a statistically significant regression model ($F=19.203$, $P<0.001$). Education level, receipt of health education, treatment modality, surgical approach, health literacy, patient communication patterns, and perceived social support were identified as significant predictors of BCRL risk perception before discharge, accounting for 39.4% of the variance in patients' risk perception levels. Detailed results are presented in Table 2.

Overall change trend of BCRL risk perception

The BCRL risk perception scores and trajectory estimates are shown in Supplementary Table 3 and Fig. 2. The results demonstrated that the total BCRL risk perception scores gradually increased from T0 to T2, peaked at T2, and then declined. While the cognitive representation dimension followed the same trend as the total scores, the emotional representation dimension reached its peak earlier at T1 rather than T2.

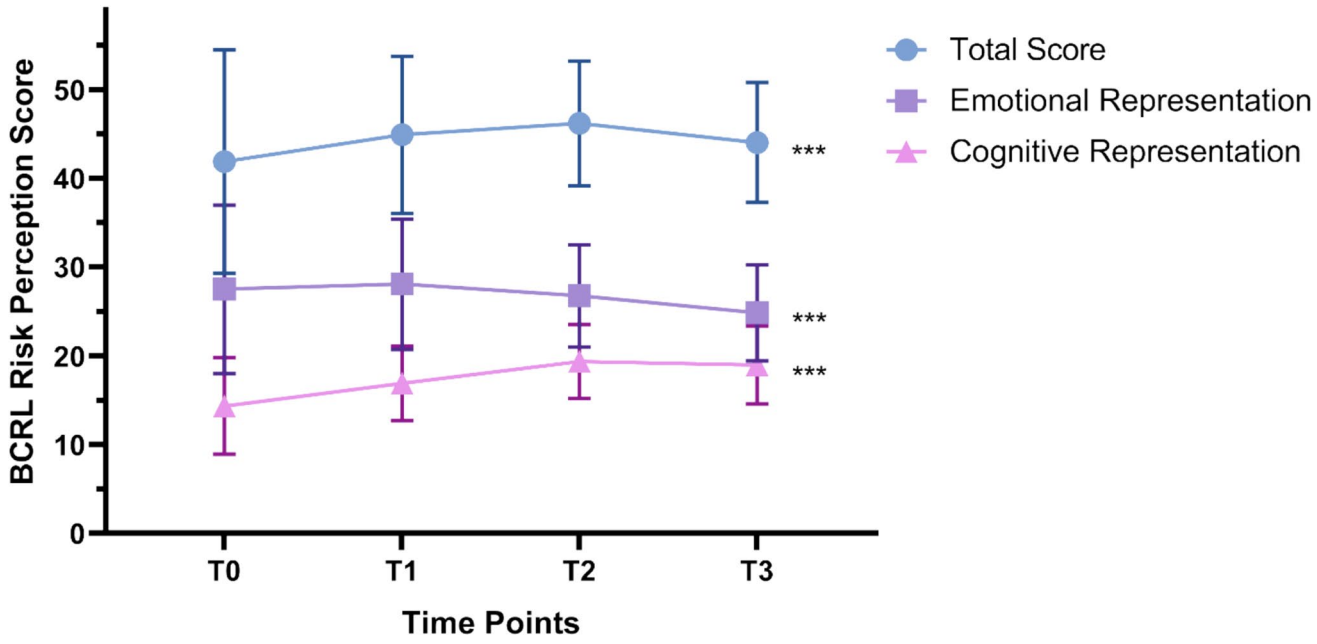

Fig. 2 Trends in total scores and dimension scores of breast cancer postoperative patients' awareness of BCRL risk during the recovery stage. Abbreviations: T0, at discharge; T1, 1 month post-surgery; T2, 3 months post-surgery; T3, 6 months post-surgery

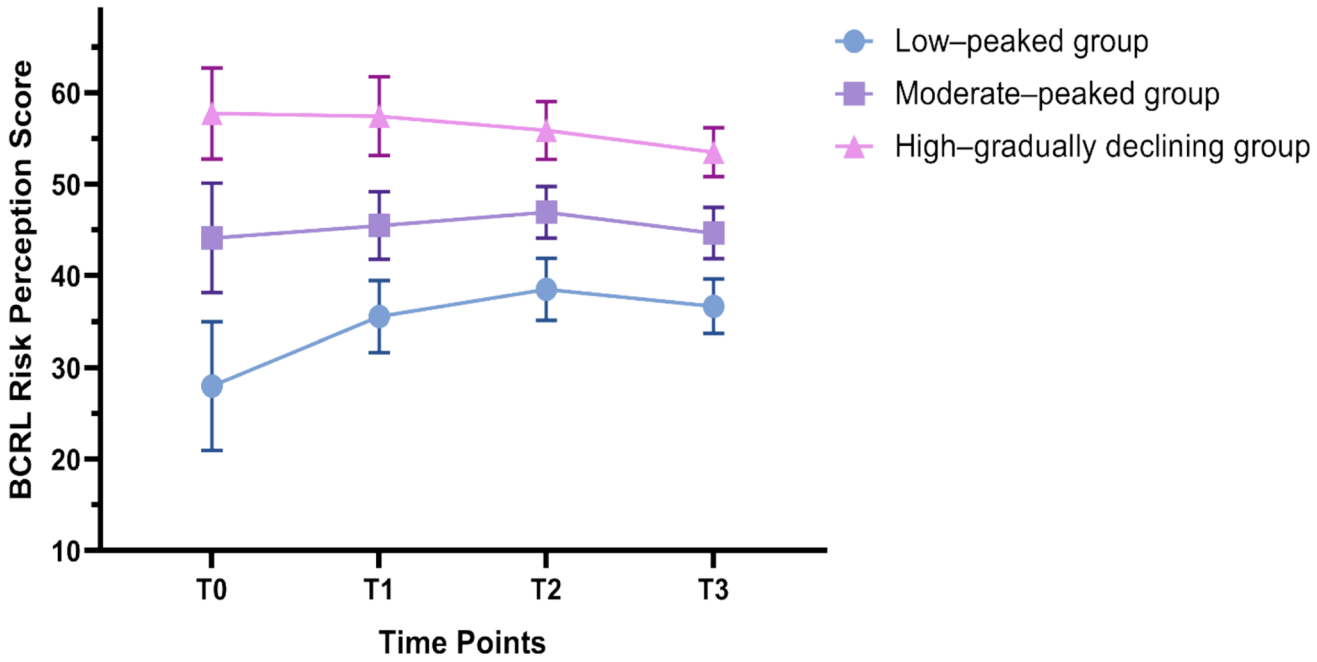

Fig. 3 Trajectories of perceived risk across the three patient subgroups from T0 to T3. Abbreviations: T0, at discharge; T1, 1 month post-surgery; T2, 3 months post-surgery; T3, 6 months post-surgery

To verify this change trajectory, we constructed a latent growth curve model (LGCM). The model fit indices demonstrated that the quadratic function model provided the best fit for the data (with the smallest AIC and BIC values, both CFI and GFI > 0.90, and SRMR < 0.05), further confirming that patients' risk perception during the first 6 months postoperatively followed a quadratic trajectory (Supplementary Table 4).

Latent classes and characteristics of BCRL risk perception trajectories

Latent class growth analysis (LCGA) results indicated that as the number of extracted classes increased from 1 to 5, the AIC, BIC, and aBIC values gradually decreased. The entropy value was > 0.85, and classification accuracy exceeded 90%. When the number of classes reached 4, the LMR value became non-significant (LMR > 0.05), indicating that the three-class model was superior to the four-class model (Supplementary Table 5). Consequently, a three-class solution was adopted. Based on their distinct changing patterns, the classes were designated as "High–gradually declining group," "Moderate–peaked group," and "Low–peaked group." The risk perception scores for each trajectory class across T0 to T3 are presented in Supplementary Table 6, and their change trajectories are depicted in Fig. 3.

Factors influencing BCRL risk perception trajectories

Variables showing statistical significance in univariate analyses were included in the multivariate logistic regression model (Supplementary Tables 7 and 8). The results revealed that, compared with the low–peaked group, receiving lymphedema health education was a significant factor for belonging to the high–gradually declining group. Patients who had received lymphedema health education were more than ten times more likely to belong to the high–gradually declining group than those who had not (OR = 11.426, 95% CI [3.014–40.311], $P = 0.001$). Higher health literacy and communication pattern scores were also associated with a greater likelihood of belonging to the high–gradually declining group. Factors influencing membership in the moderate–peaked group compared to the low–increasing group primarily included education level, surgical approach, and health literacy. Patients who underwent modified radical mastectomy were over five times more likely to belong to the moderate–peaked group than those who underwent breast-conserving surgery/mastectomy with SLNB (OR = 6.194, 95% CI [1.909–20.095], $P = 0.002$). Factors associated with membership in the moderate–peaked group compared to the high–gradually declining group mainly included receipt of lymphedema health education, treatment modality, disease stage, patient communication patterns, and social support. Patients receiving surgery alone or endocrine/targeted therapy plus surgery were approximately three times more likely to belong to the moderate–peaked group than those receiving chemotherapy plus surgery (OR = 4.939, 95% CI [1.301–18.751], $P = 0.019$ and OR = 4.443, 95% CI [1.076–18.390], $P = 0.039$, respectively). Details are presented in Table 3.

Discussion

This study is the first to systematically investigate the longitudinal developmental trajectories of BCRL risk perception in postoperative breast cancer patients. It revealed a dynamic trend of moderate overall levels, characterized by an initial slow increase followed by a slight decline. Furthermore, significant population heterogeneity in these trajectories was identified, categorizing patients into three distinct groups: "High–gradually declining group," "Moderate–peaked group," and "Low–peaked group." The study also identified the predictive roles of several factors—including education level, health education, treatment and surgical approaches, disease stage, health literacy, patient communication patterns, and social support—in determining different trajectory classifications.

Objective 1: overall change trend of BCRL risk perception during rehabilitation in postoperative breast cancer patients

The results of this study revealed an initial increase followed by a slight decrease in patients' risk perception, which differs from the trend toward stabilization within 6 months postoperatively reported by Chen et al. [28]. This discrepancy may be related to differences in healthcare resources and environments. In the study by Jing et al., patients received systematic lymphedema monitoring and intervention early after surgery, resulting in a higher baseline risk perception that remained stable. In contrast, the participants in this study had access to relatively limited healthcare resources, with insufficient monitoring and health education during the early postoperative period. This led to a delayed increase in risk perception, followed by a slight decline later, driven by changes in the rehabilitation environment and patients' adaptive adjustments.

Specifically, the relatively low level of risk perception at the pre-discharge stage (T0) may be due to patients' limited disease-related knowledge, insufficient health education, and psychological factors such as anxiety, which collectively diverted their attention from potential complications [38]. Additionally, inadequate patient-provider communication or communication styles that failed to heighten risk awareness effectively might have contributed to this initial low level [39]. The subsequent increase in scores reflects a psychological progression in patients' perception of lymphedema risk, evolving from initial awareness to gradual enhancement and eventual adaptation. During the early rehabilitation phase, a greater understanding heightened risk perception. By the T3 phase, adaptation due to continuous monitoring, the gradual transition back

Table 3 Multivariate logistic regression analysis of BCRL risk perception trajectories

	Variables	OR	95% CI	*P*
3 vs 1	Educational level			
	College or above	Ref.		
	Secondary/high school	0.066	0.015 ~ 0.291	0.001
	Health education			
	No	Ref.		
	Yes	11.426	3.014 ~ 40.311	0.001
	Health literacy	1.064	1.006 ~ 1.126	0.029
2 vs 1	Educational level			
	College or above	Ref.		
	Primary school or below	0.109	0.025 ~ 0.477	0.003
	Secondary/high school	0.114	0.032 ~ 0.409	0.001
	Breast surgery			
	BCS/mastectomy + SLNB	Ref.		
	MRM	6.194	1.909 ~ 20.095	0.002
	Health literacy	1.071	1.028 ~ 1.117	0.001
2 vs 3	Health education			
	No	Ref.		
	Yes	0.14	0.043 ~ 0.458	0.001
	Treatment modality			
	Chemotherapy + surgery	Ref.		
	Surgery	4.939	1.301 ~ 18.751	0.019
	Endocrine/targeted therapy + surgery	4.448	1.076 ~ 18.390	0.039
	Tumor stages			
	Ⅱ/Ⅲ	Ref.		
	0/Ⅰ	0.32	0.117 ~ 0.872	0.026
	Patient communication pattern	0.925	0.863 ~ 0.991	0.026
	Social support	0.925	0.871 ~ 0.982	0.011

1, high-declining group; 2, moderate-stable group; 3, low-increasing group; *BCS*, breast-conserving surgery; *SLNB*, sentinel lymph node biopsy; *MRM*, modified radical mastectomy; *Ref.*, reference

to family roles after treatment completion, and the absence of personal experience with BCRL likely contributed to a slight reduction in sustained risk attention, resulting in a modest decline in scores.

Regarding specific dimensions, emotional representation showed a slight increase at T1, which may be associated with patients' initial awareness and concern about the potential impacts of lymphedema during the early postoperative period. This was followed by a gradual decline, suggesting progressive adaptation to postoperative life, alleviation of fear and anxiety related to BCRL, and/or the active adoption of coping strategies. These findings are consistent with those reported by Sherman, indicating that emotional responses may diminish as patients adjust to their condition and develop more effective coping mechanisms [18]. Cognitive representation demonstrated an overall upward trend with a slight decrease at T3, reflecting patients' deepening understanding of lymphedema's impacts and the importance of self-management as rehabilitation progressed. The later slight decline may indicate adaptive adjustment to long-term risks, potentially related to risk perception fatigue (i.e., cognitive resource depletion from sustained attention to the same risk) [18]. This study suggests that without systematic and sustained support, patients' risk vigilance may undergo an adaptive decline during the mid-postoperative period, approximately 3 to 6 months after surgery. Therefore, clinical interventions should extend beyond the immediate postoperative period to establish a comprehensive, phased support system throughout the long-term recovery continuum. Particular emphasis is needed during the 3- to 6-month postoperative phase (T2–T3), where structured follow-ups, objective monitoring (e.g., arm circumference), and reassessment of risk perception are crucial. These measures help counteract the natural decline in risk awareness that occurs in the absence of symptoms and amid shifting life priorities, thereby sustaining patient vigilance and promoting consistent self-management.

Objective 2: heterogeneity in BCRL risk perception trajectories during rehabilitation in postoperative breast cancer patients

Using latent class growth analysis, this study identified three distinct trajectories of BCRL risk perception: the high–gradually declining group, the moderate–peaked group, and the low–peaked group. This demonstrates significant heterogeneity in risk perception within this population, consistent with the findings reported by Wu et al. [40]. The findings indicate significant variations in postoperative breast cancer patients' perceptions of and responses to lymphedema risk. The low–peaked group, characterized by the lowest initial risk perception that rose gradually, may have had inadequate early awareness, with understanding evolving later through rehabilitation experiences. Therefore, strengthening early education and establishing structured follow-up are crucial to promote timely risk recognition. The moderate–peaked group represented the largest proportion and maintained a stable level of risk perception throughout recovery. Given their adequate baseline awareness, maintenance strategies—such as periodically reinforcing key information and monitoring self-management adherence—are recommended. The high–gradually declining group began with elevated risk perception that declined over time. This pattern may reflect a rational reassessment linked to postoperative adaptation and functional recovery, or alternatively, a "risk perception fatigue" phenomenon—where sustained vigilance to a constant threat leads to attentional waning. For these patients, psychological support and tailored follow-ups are essential to maintain an appropriate level of risk awareness and ensure alignment between perceived and actual risk. Collectively, these findings underscore the value of trajectory-informed interventions: early intensive education for the low–peaked group, maintenance reinforcement for the moderate–peaked group, and strategies to mitigate cognitive fatigue for the high–gradually declining group. Such a stratified approach holds significant promise for enhancing long-term lymphedema prevention and rehabilitation outcomes.

Current research on the heterogeneity of BCRL risk perception trajectories remains limited. However, a US study using growth mixture modelling identified four distinct trajectories of recurrence risk perception in breast cancer patients [41]. The differences in trajectories between that study and ours may be attributed to factors such as assessment tools, timeframes, and sample size. These findings underscore the importance of providing differentiated, stratified, and personalized health education and support throughout the postoperative phases, which must be tailored to patients' specific trajectory classifications.

Objective 3: factors influencing different trajectories of BCRL risk perception during rehabilitation in postoperative breast cancer patients

Regarding the influence of demographic and clinical factors on risk perception trajectories, this study found that patients with higher levels of education generally demonstrated greater lymphedema risk perception and were more likely to belong to the high-perception trajectory group. This finding aligns with the results of the multiple linear regression analysis conducted at discharge. It is consistent with the study by Li et al. [42]. A possible explanation is that highly educated patients typically possess better abilities to comprehend and apply health information, along with higher self-efficacy [43], enabling them to more proactively engage in risk management behaviours, thereby maintaining heightened risk awareness.

Among the factors influencing risk perception trajectories, receiving lymphedema health education emerged as a significant predictor. Patients who had received health education exhibited higher levels of risk perception and were significantly more likely to belong to the high-perception trajectory group. This finding is consistent with previous research, indicating that health education can enhance patients' understanding of lymphedema mechanisms, risk factors, and preventive measures through systematic knowledge transfer, personalized risk assessment, and interactive learning, thereby improving their risk vigilance and judgment [44, 45].Treatment modality also significantly influenced risk perception trajectories. Patients receiving surgery alone or combined with endocrine/targeted therapy were significantly more likely to develop a moderate–peaked group than a high-declining one. Complex treatments modalities (e.g., combined radiotherapy and chemotherapy). This may be attributable to the pronounced side effects and frequent medical consultations associated with these treatments, which help maintain patients' heightened awareness of BCRL-related risks. These findings are consistent with those reported by McLaughlin [46]. In contrast, patients who underwent surgery alone may have received less comprehensive health education, thereby contributing to a lower level of BCRL risk perception. Patients receiving combined radiotherapy and chemotherapy may pay more attention to BCRL during postoperative rehabilitation due to side effects of preoperative chemotherapy, such as lymphatic vessel injury and inflammatory reactions [47]. Moreover, studies have confirmed that chemotherapy is significantly associated with an increased risk of BCRL [48]. This suggests the need for tailored risk communication based on different treatment strategies. The extent of surgery was another determining

factor, with patients undergoing more extensive procedures, such as a modified radical mastectomy, exhibiting a higher perceived risk. This is likely related to the significant impact of such surgeries on lymphatic drainage and to the need for more comprehensive preoperative communication [49, 50]. Furthermore, patients with early-stage disease (Stage 0-I) were more likely to focus on complications such as lymphedema and to belong to the moderate–peaked group. This finding differs from that of Chen et al. [28], potentially due to variations in patient concerns across disease stages. In addition, studies have shown that breast cancer patients often present negative emotions such as anxiety and depression immediately after diagnosis [51]. Patients may focus more on the psychological impact of the disease itself, while lacking sufficient awareness and attention to the risks of potential postoperative complications.

Patients with higher health literacy, more positive communication patterns, and adequate social support generally demonstrated elevated risk perception, consistent with the findings of Rutherford et al. [52]. Those with greater health literacy possess enhanced information processing and patient–provider communication skills, enabling them to more readily connect treatment specifics with personal risk, thereby forming more comprehensive cognitive and emotional assessments [53]. Positive communication helps build trust and facilitates access to personalised guidance [54], while social support enhances psychological resilience through emotional and informational assistance, consequently improving risk vigilance [55].

Notably, these factors demonstrated no significant interaction effects with time, indicating their influence remained relatively stable throughout the rehabilitation period. Given that accurate risk perception promotes adherence to risk management behaviors, we recommend providing more accessible, comprehensible health information and individualized education for patients with lower levels of education, a lack of systematic health education, simpler treatment regimens, or insufficient social support. This approach aims to improve their risk awareness and optimize long-term rehabilitation outcomes.

Limitations

Several limitations should be fully considered when interpreting the results of this study. The study sample was only recruited from two tertiary hospitals in China, resulting in limited sample representativeness, which to some extent restricted the generalizability of the findings. Although the loss to follow-up rate was comparable to that reported in similar longitudinal studies, participant attrition during the 6-month follow-up period may nonetheless have introduced selection bias. Moreover, constrained by the duration of follow-up and the exclusive analysis of baseline predictors, this study was unable to comprehensively evaluate the long-term effects of rehabilitation-related variables on risk perception. Furthermore, the associations between risk perception and other key clinical and psychological variables were not systematically examined. These factors may influence the level and evolution of risk perception, thereby limiting the interpretability of the identified trajectories.

Future studies should extend the follow-up period, incorporate additional clinical and psychological variables that may affect risk perception, and more comprehensively explore the dynamic changes in risk perception at different rehabilitation stages and their potential underlying mechanisms.

Conclusions and practice implications

In summary, this study reveals that breast cancer-related lymphedema (BCRL) risk perception among postoperative patients demonstrates dynamic changes and significant population heterogeneity. Multiple factors, including education level, health education, treatment modality, disease stage, surgical approach, health literacy, patient communication patterns, and perceived social support, primarily influence its level and developmental trajectories. These findings suggest that nursing staff should implement differentiated, individualised risk communication and educational interventions tailored to the characteristics and developmental trajectories of subgroups within each trajectory across various postoperative rehabilitation stages. Health education should particularly emphasise the mechanisms of BCRL, self-management strategies, and perceptions of controllability to enhance patients' accurate risk assessment and long-term adherence to preventive behaviours.

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Author contributions All authors contributed to the conception and design of the study. Yaru Yang, Yu An, and Mengyu Han (co-first authors) were responsible for data collection, formal analysis, and manuscript drafting. Jingming Lu, Zhiqiang He, Tianyu Wang, Hui Xiao, Junxia Ye, and Jingyu Chen participated in data curation, validation, and visualization. Jin Li (corresponding author) supervised the study, provided critical revision of the manuscript for important intellectual content, and secured ethical approval and resources. All authors have read and approved the final version of the manuscript.

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Data availability The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of The First Affiliated Hospital of Xi'an Jiao tong University (Approval No: XJTU1AF2024LLSYY-088).

Consent to participate Verbal informed consent was obtained from all individual participants included in the study.

Consent for publication The manuscript does not contain any individual person's identifiable data (including personal details, images, or videos). All participants have implicitly consented to the publication of de-identified research results as part of their informed consent to participate.

Competing interests The authors declare no competing interests.

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