



Breast cancer survivors' experiences of barriers and facilitators to lymphedema self-management behaviors: a theory-based qualitative study

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Abstract

Purpose Lifelong self-management plays a critical role in the prevention and management of lymphedema among breast cancer survivors. However, adherence to lymphedema self-management behaviors has remained suboptimal. Hence, we adopted a theory-informed method to elucidate the facilitators and barriers of lymphedema self-management for breast cancer survivors.

Methods In-depth semi-structured interviews were conducted between August and October 2022 in the lymphedema nursing clinic of a tertiary cancer hospital. The maximum variation sampling technique was used to ensure a diverse sample. The ITHBC (Integrated Theory of Health Behavior Change) framework was used to inform the interview outline and data analysis. Interview transcripts were coded line-by-line and mapped to domains in accordance with the ITHBC, using both deductive and inductive content analysis.

Results A total of 16 participants were interviewed (aged 35 to 67). Twenty-three themes (12 facilitators and 11 barriers) were mapped onto the three domains (knowledge and belief, social facilitation, and self-regulation skill and ability) of ITHBC as facilitators and barriers to lymphedema self-management. Three additional themes including limited treatment resources for lymphedema, inconvenience of lymphedema management, boredom and tedium of lymphedema self-management were categorized under the domain of other barriers.

Conclusions Incorporating these findings into the ITHBC framework allows for a more systematic selection of theory-based strategies that may improve the design of effective lymphedema self-management interventions for breast cancer survivors.

Implications for Cancer Survivors Elucidating impact factors, especially facilitators and barriers, for lymphedema self-management adherence is essential for developing effective intervention programs to enhance breast cancer survivors' lymphedema self-management behaviors.

Keywords Breast cancer-related lymphedema · Self-management · Facilitators · Barriers · Qualitative study · Content analysis

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Introduction

Breast cancer is now the most commonly diagnosed cancer worldwide, with an estimated 2.3 million new cases in 2020 alone [1]. Advances in breast cancer treatment have improved the overall survival rates and prolonged survival. However, breast cancer-related treatment can lead to various physical and psychological side effects, including lymphedema. Breast cancer-related lymphedema (BCRL) is a debilitating condition that affects approximately 21.9% breast cancer survivors [2]. It is caused by the accumulation of lymphatic fluid in the affected arm or breast area due to damage or removal of lymph nodes during treatment [3]. Lymphedema is a lifelong threat for breast cancer survivors [4]. It has been reported that the fear of developing BCRL is second only to the fear of cancer recurrence [5]. Additionally, BCRL can result in pain, swelling, decreased range of motion, and impaired physical functioning, affecting the quality of life and psychological well-being of patients [6].

Although BCRL cannot be cured, it is preventable and manageable. However, prevention and management of BCRL require survivors to adhere to lifelong lymphedema self-management behaviors (LSMB). Self-management in chronic conditions has been defined as “the intrinsically controlled ability of an active, responsible, informed and autonomous individual to live with the medical, role and emotional consequences of ones’ chronic condition(s) in partnership with social network and the healthcare provider(s)” [7]. Our previous research demonstrated that self-management strategies can significantly reduce the risk of developing lymphedema and prevent its advancement [8]. Furthermore, current guidelines also highlight the significance of self-management, including regular exercise, skin care, lymphatic drainage, monitoring for early signs of lymphedema, etc., to prevent lymphedema and manage its symptoms [4, 9, 10]. However, despite the benefits of self-management, adherence to LSMB can be challenging [11]. Studies have shown that adherence to LSMB is suboptimal among breast cancer survivors, with the adherence rates ranging from 19.5 to 39.1% [10, 12, 13]. For example, a cross-sectional study conducted among 102 breast cancer survivors with lymphedema found that only 39.1% of the women implemented regular self-care [13]. Similarly, a longitudinal study showed that the adherence to LSMB decreased over 12 months of follow-up [14].

Elucidating impact factors, especially facilitators and barriers, for LSMB adherence is essential for developing effective intervention programs to enhance survivors’ lymphedema self-management behaviors. Efforts have been devoted to understand the underlying reasons for

non-adherence to LSMB among breast cancer survivors. Several quantitative research studies on this issue suggested that breast cancer survivors faced a range of barriers to LSMB, including lack of knowledge, lower self-efficacy, lack of self-regulation ability, etc. [12, 13, 15, 16]. Strategies to increase adherence to LSMB are likely to be more effective if they are informed by in-depth exploration of survivors’ experiences of personal self-management practices, probing both barriers and facilitators to LSMB. Some researchers utilized qualitative research to explore the factors influencing LSMB from survivors’ perspectives [17–20]. Ostby et al. (2018) investigated breast cancer survivors’ perceptions on barriers to LSMB and identified a range of barriers including lack of information, emotional distress, and physical limitations [18]. Zhao et al. (2021) explored both patient and healthcare professional experiences of LSMB, identifying facilitators such as access to information, social support, and healthcare professionals’ involvement [20].

Previous studies have used mainly inductive methods to identify facilitators and barriers of LSMB adherence, which can reveal additional barriers from survivors’ perspectives, but may be less intuitive to researchers [21]. Deductive qualitative research, guided by theory, involves a clear research question to avoid data overload. It provides advantages of clarity, replicability, structure, and generalizability by testing predefined theories or hypotheses, leading to findings applicable to larger populations or contexts [22]. As far as we know, there has been no study investigating the issue of LSMB adherence among breast cancer survivors using in-depth interviews guided by a theoretical framework. Behaviors change theories provide valuable tools for understanding and structuring the reasons behind adherence and non-adherence to certain behaviors, and allow researchers to systematically and explicitly investigate mechanisms of behavior change. Moreover, interventions based on theory are suggested to be more successful in changing behaviors [23].

Given the challenges associated with LSMB, there is a growing need to better understand survivors’ perspectives on its facilitators and barriers. Therefore, this study aims to explore potential facilitators and barriers of LSMB using both inductive and deductive qualitative approach with phenomenology design, based on the Integrated Theory of Health Behavior Change (ITHBC) framework [24].

Theoretical framework

ITHBC, developed by Ryan (2009), is a comprehensive and practical model for understanding and promoting health behavior change [24]. The ITHBC integrated key constructs from multiple well established health behavior theories and

models, including theories of health behavior change, self-regulation theories, social support theories [24]. It proposes that behavior change in health can be stimulated through a combination of enhanced knowledge and awareness of health beliefs, improved social support, and increased ability to self-regulate skills and abilities. This theory has been applied in various healthcare settings, including weight self-management, health promotion programs, and medication adherence [25–28]. By using ITHBC, these studies were able to identify factors that affect health behaviors and develop effective interventions to promote health behaviors [26, 27]. Therefore, ITHBC is a valuable tool for researchers and healthcare practitioners to better understand and address health behavior change.

Methods

Design

This is a descriptive qualitative study using ITHBC as the theoretical framework to gain an in-depth understanding of facilitators and barriers for breast cancer survivors to perform lymphedema self-management behaviors. We reported the study following the Consolidated Criteria for Reporting Qualitative Research (COREQ) [29].

Setting

The study was conducted in the Lymphedema Nursing Clinic and Breast Cancer Rehabilitation Nursing Clinic, in a 2000-bed tertiary cancer institute and hospital in Tianjin, China. This hospital is one of the top five cancer centers in China, with a breast cancer research center of 400 beds. The Lymphedema Nursing Clinic is staffed with three lymphedema therapists who provide lymphedema consultation, monitoring, self-management guidance, and complete decongestive therapy (CDT) treatment to patients who have undergone breast cancer surgery. Meanwhile, the Breast Cancer Rehabilitation Nursing Clinic mainly provides post-operative rehabilitation consultation and guidance for breast cancer survivors, including functional exercises, psychological counseling, and so on.

Participants

Between August and October 2022, post-surgery breast cancer survivors over 18 years old, who had previously participated in a cross-sectional study on lymphedema self-management behaviors, were purposively selected and interviewed. The maximum variation sampling technique

was used to ensure a diverse sample across various factors, such as self-management behaviors, age, education levels, post-surgery time, employment status, types of surgery, and length of lymphedema diagnosis. Breast cancer survivors were excluded from the study if they had other malignant tumors, tumor recurrence or metastasis, a history of lymphatic diseases or primary lymphedema, serious comorbidities limiting their participation, cognitive impairment or mental disorders, or were unaware of their breast cancer diagnosis.

All participants who were approached agreed to participate and were scheduled for interviews. They were informed that their participation was voluntary and were requested to complete a consent form if they agreed to take part. The interviews took place at the lymphedema nursing clinic on a day chosen by the participants. The sample size was determined based on data saturation, indicating no new codes emerged in three consecutive interviews after analyzing at least ten interviews [30]. Nineteen patients were approached, with 3 of them refusing to participate in due to schedule conflicts.

Data collection

Semi-structured face-to-face interviews were conducted to explore and understand the personal meanings, experiences, and issues pertinent to breast cancer individuals in the context of their LSMB. The interview guide (see Table 1) was developed based on the ITHBC framework, under the guidance of a qualitative research methodology expert and a lymphedema research specialist. All questions were open-ended, general, and focused on the topic of lymphedema self-management. Two pilot interviews were conducted to test and refine the interview guide, as well as to enhance data collection plans and formulate pertinent lines of questioning. Pilot interviews were not analyzed. Before each interview, the interviewer familiarized with each participant by self-introduction and providing information about the study, and collected demographic information, disease and treatment-related information, as well as lymphedema information. The interview setting was quiet and free from distractions. To ensure consistency, all interviews were conducted by the same researcher (AM Shen), a female PHD-prepared oncology nurse with experience of breast cancer care and qualitative study. The interviewer skillfully employed timely follow-up questions based on the respondents' answers and promptly recorded the main points conveyed by the interviewees, as well as their facial expressions, tone of voice, pauses, and other non-verbal cues. All interviews were audio-recorded, and lasted between 21 and 63 min.

Table 1 Semi-structured interview guide based on ITHBC

| ITHBC component | Interview questions |
|------------------------------------|---|
| Knowledge and belief | 1. What do you know about breast cancer-related lymphedema? |
| | 2. What do you know about lymphedema self-management? |
| | 3. How do you view the self-management of lymphedema? |
| | 4. How do you manage lymphedema in your daily work and life? |
| | 5. How do you handle situations where self-management of lymphedema conflicts with other aspects of your personal or professional life? Could you provide a specific example? |
| Self-regulation skills and ability | 6. What is your evaluation of the current effectiveness of self-management for lymphedema? |
| | 7. What specific goals or outcomes are you aiming to achieve through self-management of lymphedema? |
| | 8. How confident are you in your ability to effectively self-manage lymphedema? Have you observed any changes in your self-confidence during the process of self-management? |
| | 9. What psychological or emotional challenges have you faced during the process of self-managing lymphedema? How have you coped with them? |
| Social facilitation | 10. In your opinion, what are the facilitating and hindering factors in self-management of lymphedema? |
| | 11. Who or what sources have influenced your motivation to engage in self-management of lymphedema or prioritize it? |
| | 12. During your journey of self-managing lymphedema, who has provided you with support or assistance? |
| | 13. What additional support do you believe is needed during the process of self-management for lymphedema? |

Data analysis

The transcripts were analyzed and coded using NVivo 12 software. Initially, all interview recordings were automatically transcribed, followed by careful review by the researchers to correct errors and make necessary modifications. Supplementary notes taken during the interviews were incorporated into the transcriptions. To maintain the integrity of the original concepts, the data analysis was conducted in the language of the original text (Chinese). A directed content analysis approach, combining both inductive and deductive approaches, was employed [31]. Prior to the analysis, a list of initial themes and categories (deductive codes) was established based on the constructs of ITHBC framework. Topics that did not fit within the existing codes were categorized under separate headings as inductive codes. Two researchers (AMS, FZ) extensively reviewed the transcriptions to enhance familiarity and identify content aligning with the predefined categories. Sentences and phrases were treated as meaningful units for coding the interview text, with codes assigned to the relevant categories based on conceptual similarity. Upon completion of the coding process, codes related to similar barriers, facilitators, or other themes were grouped together. The frequency of each code was documented and influenced the wording and extent of the themes, with greater impact given to codes appearing more frequently. A third researcher (QL) conducted a “sense-check” on a selected portion of the final themes, codes, and extracts. Transcripts and themes were not returned to the participants for verification or feedback. Quotes were included in the manuscript to accurately reflect the intended meaning of the participants.

Ethical considerations

This study was approved by the Biomedical Ethics Committee of Peking University (Approval number: IRB 00001052–21123) prior to the commencement. Prior to data collection, explicit and documented consents were acquired from all participants. The study process was entirely voluntary, anonymous, and confidential.

Results

Participant characteristics

A total of 16 participants, aged from 35 to 67 years old, were interviewed. All but one of the patients were married, and seven of them were employed. Ten (62.5%) participants received high school education or above. Twelve participants had the tumor located in right breast. Two third of them underwent mastectomy surgery, while four participants received lumpectomy. Majority (12/16) of the interviewees undergone axillary lymph nodes dissection (ALND). Eight participants were diagnosed with lymphedema, with five of them received CDT. Five participants had the sign of early-stage lymphedema. All participants received at least two kinds of adjuvant treatments. Table 2 outlines participants' characteristics.

Barriers and facilitators to lymphedema self-management behaviors

Participants identified various barriers and facilitators to engaging in LSMB, which fit within the pre-determined

Table 2 Characteristics of participants

| Characteristics | Sample, <i>n</i> (%) |
|--------------------------|------------------------------------|
| Age, years | Mean 51.25, SD 10.18, range: 35–67 |
| Marital status | |
| Married | 15 (93.75) |
| Unmarried | 1 (6.25) |
| Education | |
| Primary School | 1 (6.25) |
| Middle school | 1 (6.25) |
| High school | 4 (25.00) |
| Secondary vocational | 1 (6.25) |
| College | 4 (25.00) |
| University | 5 (31.25) |
| Employment | |
| Employed | 7 (43.75) |
| Unemployed | 2 (12.50) |
| Retired | 7 (43.75) |
| Tumor location | |
| Left | 4 (25.00) |
| Right | 12 (75.00) |
| Time post-surgery | |
| < 1 year | 5 (31.25) |
| 1–3 years | 6 (37.50) |
| > 3 years | 5 (31.25) |
| Type of surgery | |
| Mastectomy | 12 (75.00) |
| Lumpectomy | 4 (25.00) |
| Type of axillary surgery | |
| ALND | 12 (75.00) |
| SLNB | 4 (25.00) |
| Treatment received | |
| NAC | 6 (37.50) |
| AC | 14 (87.50) |
| RT | 10 (62.50) |
| TT | 5 (31.25) |
| ET | 13 (81.25) |
| Diagnosis of LE | |
| Yes | 8 (50.00) |
| No | 8 (50.00) |

Abbreviations: *ALND* axillary lymph node dissection, *SLNB* sentinel lymph node biopsy, *NAC* neoadjuvant chemotherapy, *AC* adjuvant chemotherapy, *RT* radiotherapy, *TT* targeted therapy, *ET* endocrine therapy

ITHBC constructs, including knowledge and belief (knowledge, personal perceptions, self-efficacy, outcome expectancy, goal congruence), social facilitation (social influence and social support), and self-regulation skills and ability. Table 3 provides an overview of the mapping of 23 themes onto the ITHBC framework as barriers and facilitators to

LSMB in breast cancer survivors. Three themes were categorized under the domain of other barriers.

Domain 1: Knowledge and belief

Knowledge

According to the ITHBC, knowledge is defined as condition-specific factual information [24]. Some participants ($n=4$) mentioned that having sufficient knowledge of lymphedema self-management empowered them to engage in self-management activities. While nearly half of the participants ($n=7$) attributed their difficulty in effectively self-managing lymphedema to a lack of knowledge regarding lymphedema and its management strategies.

“I feel that I have gained a good understanding of lymphedema knowledge. I have learned how to be careful at home to prevent swelling and how to incorporate exercise into my routine. I am still eager for healthcare professionals to continue providing us with additional information in the future.” (P14, aged 58, non-lymphedema).

“I’m uncertain about how to prevent swelling. I have noticed that when I exert myself or become fatigued, my arm tends to swell. However, I haven’t given much thought to prevention or know what specific actions to take. Nevertheless, I do my best to minimize the use of that arm.” (P10, aged 39, lymphedema).

Personal perceptions

Personal perceptions of lymphedema were verified as influence factors on LSMB. Participants reported different perceptions on lymphedema and its management. Among these, perception of the threats and negative impacts of lymphedema ($n=9$), perception of the importance ($n=9$), and the benefits ($n=4$) of lymphedema self-management acted as facilitators.

“My arm is seriously swollen. I can’t even wear those bulky winter jackets with the extra roomy sleeves. If I don’t take good care of my lymphedema, it really messes up my daily life.” (P3, aged 46, lymphedema)
“Moreover, personally, I consider this lymphedema management work to be extremely important.” (P11, aged 48, non-lymphedema)

“You know, if I take a moment to stretch and drainage before going to sleep, the tightness in my arm quickly subsides. I think this is a daily routine that must not be overlooked or skipped. I mean, seriously, cannot be skipped.” (P11, aged 48, non-lymphedema).

Table 3 Facilitators and barriers to lymphedema self-management based on the ITHBC framework

| Domain (<i>n</i>) | Theme (<i>n</i>) | Quotation |
|--|---|---|
| Knowledge and belief (<i>n</i> = 15): Knowledge is defined as condition-specific factual information, and beliefs are defined as personal perceptions about the specific health condition or health behavior Facilitators (<i>n</i> = 10) | Adequate knowledge of self-management (<i>n</i> = 4) | The medical staffs warned me about the risks of lymphedema, and I also looked up some relevant information online. Basically, I learned what to watch out for to prevent swelling. (P11) I believe I've mostly grasped it now. I've learned how to be cautious at home to prevent swelling and how to engage in exercise. And naturally, I look forward to the medical staff continuing to provide us with more information in the future. (P14) |
| | Lack of knowledge about lymphedema and management strategies (<i>n</i> = 7) | I didn't know much about this. Maybe doctors or nurses mentioned it before, but I didn't pay much attention. So, I didn't really think it was a big deal. I thought swelling was a normal thing, especially after surgery. I just ignored it, thinking it was nothing to worry about. (P9) No one told us, and we had no clue how bad it could be when you're swollen. Who would have known it would cause so much trouble? If we had known earlier, we would have been more careful. (P12) |
| Personal perceptions (<i>n</i> = 15) Facilitators | Perception of the threats and negative impacts of lymphedema (<i>n</i> = 9) | My arm is seriously swollen. I can't even wear those bulky winter jackets with the extra roomy sleeves. If I don't take good care of my lymphedema, it really messes up my daily life. (P3) I've encountered similar situations before, you know? Like with older ladies who already had swollen arms. It made me think that, compared to them, we're still young, and our personal appearance matters a lot too, you know? So, we really need to take it seriously and give it the attention it deserves. (P11) |
| | Perception of the importance of lymphedema management (<i>n</i> = 9) | Moreover, personally, I consider this lymphedema management work to be extremely important. (P11) I totally agree! It's really important because it's about our own well-being, right? No one else can take care of it for us, so we have to treat it as a top priority. Besides, I feel like nothing is more important in my life right now than taking care of myself. Everything else comes second. (P13) |
| Barriers | Perception of the benefits of lymphedema management (<i>n</i> = 4) | I've been doing the whole drainage massage thing every day, taking care to protect my arms, and now I feel pretty healthy. (P4) You know, if I take a moment to stretch and drainage before going to sleep, the tightness in my arm quickly subsides. I think this is a daily routine that must not be overlooked or skipped. I mean, seriously, can't be skipped. (P11) |
| | Insufficient perception of threats of lymphedema and importance of lymphedema self-management (<i>n</i> = 9) | Sometimes, I get tired when I spend too much time looking at my phone at night. I would feel my arm getting a bit tired, but the next day it didn't swell, and even though I felt tired again, it still didn't swell. So, I didn't really pay much attention to it. (P12) Maybe I just didn't think it was a big deal and didn't see the need to take action. It's like, I didn't really pay attention to it unless it became more severe and serious. That's when I would start to focus on it. (P16) |

Table 3 (continued)

| Domain (<i>n</i>) | Theme (<i>n</i>) | Quotation |
|--|--|--|
| Self-efficacy (<i>n</i> = 8): confidence in one's ability to successfully engage in a change in normal and stressful situations | Facilitators | Being confident to manage lymphedema (<i>n</i> = 7) To be honest, I haven't been diligent in managing it, but deep down, I have this confidence. I believe that if I take it seriously and manage it properly, it will have an effect. That's how I see it. (P5) I'm pretty confident because I have a strong resilience. If I set my mind on something and want to persist, I can generally achieve it. (P3) I feel like it's really difficult to manage myself on my own, honestly. (P2) |
| | Barriers | Lack of confidence to self-manage lymphedema (<i>n</i> = 1) Once I've got it under control, I can just strut around every day, swinging my arms and feeling all blissed out. That'd be pure happiness! (P3) Of course, in the future, I believe it can go back to how it was before. That way, I know I have to stay committed to it (lymphedema self-management). (P8) |
| Outcome expectancy (<i>n</i> = 8): one's belief that engagement in a behavior will result in desired results | Facilitators | High expectancy for lymphedema self-management (<i>n</i> = 7) Honestly, I feel skeptical about the idea that simply wearing a bandage without medication or anything else would make it go away. That's why I didn't seek treatment initially, you know? (P11) I tried looking for exercises and massage techniques myself, or doing some stretching exercises and such. But I didn't really see significant results, so I stopped doing them. (P13) |
| Barriers | Low expectancy for lymphedema self-management (<i>n</i> = 3) | |
| | | |
| Goal congruence (<i>n</i> = 10): resolution of confusion and anxiety occurring from apparent contradictory and competing demands associated with health goals | Facilitators | First and foremost, I prioritize my own mental well-being and physical condition. I've put myself first now, whereas before, I would focus on taking care of the elderly or children. (P11) Health comes first, and now I'm starting to pay attention to managing the swelling. At least, I can say that our financial situation at home has improved compared to before. And as for the kids, they have grown up, so I don't have to worry about them as much. It's comforting to know that. Now, the whole family wants me to get my arm treated and healed. (P4) |
| Barriers | Lymphedema self-management conflicting with family and social role (<i>n</i> = 7) | The downside is that there are certain chores and household responsibilities that I have to handle. You know, there's no way around it. You can't just sit back and do nothing. (P13) Well, right now I'm a bit busy with work, and it can make it difficult to find time to do these (lymphedema self-management) things. During the day, I'm at the office, so it's not feasible to take too much time away from my desk. (P16) |
| | Poor role switching (<i>n</i> = 1) | Actually, my family members don't even want me to do the household chores. It's just me being overly eager to do things on my own. (P8) |

Table 3 (continued)

| Domain (<i>n</i>) | Theme (<i>n</i>) | Quotation |
|--|---|--|
| Self-regulation skill and ability (<i>n</i> = 14): self-regulation refers to a process that people use as they incorporate a behavior change into their daily routines and lifestyles Facilitators | Strong self-regulation skills and abilities for lymphedema self-management (<i>n</i> = 12) | <p>(1) Goal setting So, I think it's important not to let lymphedema escalate too much and not to let it affect our daily lives too much. Since we are at the risk (of lymphedema), the key is to take care of ourselves and be attentive to our own well-being. (P6)</p> <p>(2) Self-monitoring and reflective thinking Actually, I should admit that I haven't been doing a great job with my self-management of lymphedema. There are many things I could have done to prevent it, but I didn't take those steps, so I feel like I haven't done well in that regard. (P16)</p> <p>Sometimes when I do aerobics, I occasionally experience a slightly increased range of motion. I instinctively remain attentive, ensuring that the range of motion does not become excessive, and try not to let the affected limb stretch too much. (P11)</p> <p>(3) Planning and plan enactment I plan to watch a video to divert my attention when I do the manual lymph drainage. Because if you only do this one thing, you will feel that time is very slow. (P8)</p> <p>For example, if I have 20 min of exercise scheduled for the day and I know I'll be busy at work, I can do it in the evening when I get home or find other opportunities like doing some hand exercises while watching TV. So, I don't see any conflict in fitting it into my day as long as I plan it well and prioritize completing it. (P6)</p> <p>(4) Management of emotional response When I can't calm down, I practice mindfulness breathing, and it feels great. (P2) Sometimes, when my arm feels uncomfortable and my mood becomes irritable, I quickly adjust myself. I either ask a family member to massage my arm or I lift it up and let it hang for a while, to alleviate the discomfort. (P3)</p> <p>(5) Lymphedema self-management strategies Moreover, once it becomes a habit, it doesn't require much time investment. I just do it (manual lymphatic drainage) while getting ready in the morning, like during my morning routine. (P11) Because lifting heavy objects or experiencing injuries can potentially trigger lymphedema, it's important to control and protect oneself. When it comes to lifting heavy objects, I completely rely on others and avoid doing it myself. (P11)</p> |
| Barriers | Poor self-regulation skills and abilities for lymphedema self-management (<i>n</i> = 7) | <p>I'm not sure how to manage it exactly, but I'm really paying attention to this issue now. When my arm swells up, it feels heavy and tiresome to move it, which makes me uncomfortable and frustrated. (P3) If I feel uncomfortable, I just try to move around a bit and take a break. I don't dwell on why I'm feeling uncomfortable, I just tell myself to pay more attention and maybe tomorrow it will be better. I try to be mindful and not overexert myself today, and I believe that resting a bit tomorrow will make me feel better. I try not to think too much about how tired or uncomfortable I am today. (P15)</p> |

Table 3 (continued)

| Domain (<i>n</i>) | Theme (<i>n</i>) | Quotation |
|---|--|---|
| Social facilitation (<i>n</i> =15) | | |
| Social influence (<i>n</i> =7): People experience social influence when a knowledgeable person in a position of perceived authority sways their thinking and motivation, leading to engagement in behavior | | |
| Facilitators | Positive social influence (<i>n</i> =5) | <p>Self-management is crucial, you know. I have this aunt who had surgery more than 10 years ago, and she's doing great, no swelling at all. She told me that if you don't take care of it properly, your arm could turn into what? A rubbery arm! That's why I'm so vigilant and pay attention to it every single day. (P8)</p> <p>The doctor told me that exercise is essential for preventing swelling, so every morning when I brisk walk, I do this motion of lifting my arm up or raising it. Sometimes I would just lift it on my own like that. (P10)</p> |
| Barriers | Negative social influence (<i>n</i> =3) | <p>I have two examples around me. One is my cousin, who had surgery 20 years ago. She didn't take any medication or have follow-up visits, and she didn't let it affect her daily activities. Her arm didn't swell either. And then there's my elder sister, who had a complete mastectomy. She does all the household chores by herself, and although she has some swelling, she's perfectly fine. So, initially, I overlooked this issue because I saw that they were doing fine and didn't pay much attention to it. (P9)</p> <p>I've also consulted with doctors, and they mentioned that there isn't a perfect solution for it. So I just thought that if it swells, there's not much that can be done about it. Since there isn't a clear solution, I ended up neglecting the issue. (P9)</p> |
| Social support (<i>n</i> =15): consists of emotional, instrumental, or informational support, which facilitates engagement in a health behavior | | |
| Facilitators | Information support from families, peers, and medical staffs (<i>n</i> =10) | <p>Sometimes my family helps me look things up, and then they let me know. Like before, I wanted to clean the floor, so I asked if it was okay. And my partner checked online and found out that doing repetitive movements like that isn't recommended. They told me, and ever since then, I've known not to do it. (P14)</p> <p>We even suggested having a talk about lymphedema, and we all liked the idea. It would be cool to have more events like that to learn more and gain strength. (P14)</p> |
| | Instrumental support from families and colleagues (<i>n</i> =13) | <p>My husband is very supportive of me. We're not particularly wealthy, but we can still afford bandages and sleeves. He's really supportive, and whenever I mention a need, he immediately buys them for me. Sometimes he even helps me wrap the bandages. My family is very supportive overall. (P1)</p> <p>At my workplace, my coworkers are really supportive. They don't assign me any physically demanding tasks anymore, and they've made the work schedule flexible for me. They say that if I feel better, I can come to work, but if I am not feel good, they encourage me to take more time off and rest at home. (P13)</p> |

Table 3 (continued)

| Domain (<i>n</i>) | Theme (<i>n</i>) | Quotation |
|---------------------|---|--|
| Barriers | Emotional support from families, peers, and medical staffs (<i>n</i> =9) | As soon as I saw such great results in reducing the swelling, I took a photo and posted it in our family WeChat group. They all gave me thumbs up and said, "Wow, you're recovering so well! Keep it up, keep it up!" They were really encouraging. (P1) Even the nurses and educators who teach me about lymphedema management provide comfort and support. Their explanations and guidance serve as emotional support and give me strength. (P5) |
| | Insufficient family instrumental support (<i>n</i> =2) | Me and my spouse, we do it ourselves. We sit down and figure out how to put on the bandage together. You know, my spouse has a bit of a short temper and he's not used to doing these delicate tasks. Sometimes, when things don't go smoothly, he gets frustrated and doesn't feel like helping me anymore. (P1) |
| | Lack of emotional support, especially from families (<i>n</i> =4) | I believe that the family's self-management of lymphedema is very important. I know a patient, she must be divorced, and the child is not with her. She just couldn't get rid of the edema, and she was in a particularly bad mood. So, the warmth of the family is really important. (P2) I don't have much (support) at work. How should I say at work? They are all colleagues, and they may not care enough about you, and it has nothing to do with them, so it's okay to do whatever you want at work. (P16) |
| Other barriers | Lack of professional information support from health-care providers (<i>n</i> =11) | The massage techniques I found online were different from the ones taught by the nurses here. Online, they recommended using the thumb to apply pressure. It was only later when the nurse corrected me that I realized I had been doing it wrong before. (P12) In the past, I considered buying compression sleeves. I checked on Taobao and JD.com, but I didn't know which ones were suitable. I didn't receive any guidance from the doctors or nurses, and I didn't know who to ask, so I didn't dare to buy them without proper guidance. (P16) |
| | Limited treatment resources for lymphedema (<i>n</i> =1) | And those people can find places to get treatment too, you know? They say a lot of people these days have heard about it, like when I first got swollen, they said there's nowhere to get treated, don't know where to go. With all these communication methods nowadays, there are also a lot of closed channels for information, you know what I mean? (P1) |
| | Lymphedema management can be inconvenient (<i>n</i> =2) | You know, once I go back, if I have to wear bandages every day, it definitely won't meet my basic lifestyle needs. It won't fulfill my requirements, and I'll feel inconvenienced by it. (P10) During this period of wearing bandages, it's not convenient to use a leather belt like that. It's not easy to fasten, and even pulling up my pants with multiple layers becomes quite a struggle. It's just not convenient at all. (P1) |
| | Lymphedema self-management is boring and tedious (<i>n</i> =1) | I just feel that doing this lymph drainage for such a long time is time-consuming and quite bothersome, so I'm not really keen on doing it. (P8) |
| | | |

Participants with insufficient perception of threats of lymphedema and importance of lymphedema self-management ($n=9$) found it difficult to perform LSMB.

“Before I went to seek medical advice, I didn’t really think much of it. I thought it wasn’t a big deal and didn’t bother me at all.” (P4, aged 49, lymphedema)

Self-efficacy

Self-efficacy refers to “the confidence in one’s ability to successfully engage in a change in normal and stressful situations” [24]. Some participants described that they were confident to manage lymphedema, which facilitate participants’ engagement in LSMB.

“I’m pretty confident because I have a strong resilience. If I set my mind on something and want to persist, I can generally achieve it.” (P3, aged 46, lymphedema)

Only one participant felt that it was challenging for her to self-manage lymphedema.

“I feel like it’s really difficult to manage myself on my own, honestly.” (P2, aged 61, lymphedema)

Outcome expectancy

The definition of “Outcome expectancy” is one’s belief that engagement in a behavior will result in desired results [24]. High outcome expectancy of lymphedema self-management acted as motivators to self-management behaviors. Seven participants reported high expectancy of lymphedema self-management during the interview.

“Of course, in the future, I believe it can go back to how it was before. That way, I know I have to stay committed to it (lymphedema self-management).” (P8, aged 35, non-lymphedema)

Still, a few of participants showed low expectancy for lymphedema self-management, especially for those who have been adhering to the management for a while but have not experienced any improvement.

“Honestly, I feel skeptical about the idea that simply wearing a bandage without medication or anything else would make it go away. That’s why I didn’t seek treatment initially, you know?” (P11, aged 48, non-lymphedema)

Goal congruence

Goal congruence is defined as “the resolution of confusion and anxiety occurring from apparent contradictory and

competing demands associated with health goals” [24]. During the interview, we found that some survivors consistently prioritized their own health and lymphedema management ($n=4$). These participants were more likely to engage in effective lymphedema self-management practices.

“My grandson occasionally visits and asks me to hold him. Since he is still young, I can’t refuse him, but I do have some concerns. As a precaution, I typically hold him for about a minute and then gently put him down. I tell him that I need to be cautious with my arms. That’s why I pay extra attention and try my best not to do these things.” (P15, aged 59, non-lymphedema).

However, several participants experienced challenges with goal congruence, such as conflicts between lymphedema self-management and family or social responsibilities ($n=7$), as well as difficulties in switching between different roles ($n=1$), which they perceived as barriers.

“The downside is that there are certain chores and household responsibilities that I have to handle. You know, there’s no way around it. You can’t just sit back and do nothing.” (P13, aged 51, lymphedema)
 “Actually, my families don’t even want me to do the household chores. It’s just me being overly eager to do things on my own.” (P8, aged 35, non-lymphedema)

Domain 2: Self-regulation skill and ability

Self-regulation refers to a process that people use as they incorporate a behavior change into their daily routines and lifestyles [24]. This process consists of goal setting, self-monitoring and reflective thinking, planning and plan enactment, management of emotional response, etc. Strong self-regulation skill and ability for lymphedema self-management was an obvious facilitator.

“So, I think it’s important not to let lymphedema escalate too much and not to let it affect our daily lives too much. Since we are at the risk (of lymphedema), the key is to take care of ourselves and be attentive to our own well-being.” (P6, aged 56, non-lymphedema).

“I plan to watch a video to divert my attention when I do the manual lymph drainage. Because if you only do this one thing, you will feel that time is very slow.” (P8, aged 35, non-lymphedema)

“Sometimes when I do aerobics, I occasionally experience a slightly increased range of motion. I instinctively remain attentive, ensuring that the range of motion does not become excessive, and try not to let the affected limb stretch too much.” (P11, aged 48, non-lymphedema).

“When I can’t calm down, I practice mindfulness breathing, and it feels great.” (P2, aged 61, lymphedema)

“I consciously use my left hand for certain tasks now. For example, I use the mouse with my left hand on the computer. It’s a conscious effort to exercise and share the workload with my right hand.” (P6, aged 56, non-lymphedema).

Some participants indicated that they did not know how to cope with problems occurring during lymphedema management, which could be concluded as poor self-regulation skill and ability.

“The sleeve is too tight. When I first purchased it, I tried wearing it a few times, but each time it took me a long time to put it on, and I couldn’t get it fitted properly.” (P3, aged 46, lymphedema)

“I often get bored while doing exercises, and sometimes I stop doing them after just one or two minutes.” (P8, aged 35, non-lymphedema)

Domain 3: Social facilitation

Social influence

People experience social influence when a knowledgeable person in a position of perceived authority sways their thinking and motivation, leading to engagement in behavior. Social influence, mainly from peer patients and medical staffs, was identified as both facilitator and barrier to lymphedema self-management. Patients with positive social influence were motivated to lymphedema self-management.

“The doctor told me that exercise is essential for preventing swelling, so every morning when I brisk walk, I do this motion of lifting my arm up or raising it. Sometimes I just lift my arm like that.” (P10, aged 39, lymphedema).

On the contrary, peer patients and medical staffs can also bring about some negative social influences, especially peer patients, which influenced their self-management adherence.

“I’ve seen my fellow patients with swollen arms and they manage to endure it without doing anything, so I didn’t think much of it either.” (P13, aged 51, lymphedema)

Social support

Social support consists of emotional, instrumental, or informational support, which facilitates engagement in a health behavior. Participants received various support from their social network, such as information support ($n = 10$) and

emotional support ($n = 9$) from families, peers, and medical staffs, instrumental support from families and colleagues ($n = 13$).

“The support from medical professionals is also important. They teach us knowledge, give us professional advice, and provide tools (measuring taps). Trying to measure my arm size at home with a tape measure didn’t really work.” (P8, aged 35, non-lymphedema).

“Both my family and my workplace have been very supportive. My employer has lightened my workload, and my family tries their best to minimize my household chores. This support ensures that I don’t feel overwhelmed by additional responsibilities at home.” (P9, aged 46, lymphedema).

“Sometimes, I confide in my fellow patients and share my emotions with them. We can relate to each other and understand each other’s experiences.” (P4, aged 49, lymphedema).

However, many participants reported insufficient social support, including insufficient family instrumental support ($n = 2$), lacking of emotional support from family members ($n = 4$), and lacking of professional support from health-care providers ($n = 11$), which were perceived barriers to lymphedema self-management.

“My spouse doesn’t take care of me much either. He never says, ‘Let me help you with these things.’ It just doesn’t happen.” (P10, aged 39, lymphedema)

“Perhaps what bothers me the most is the lack of care from my family. My husband is not very talkative, and sometimes I feel like he doesn’t care me. As for work, it’s fine, nothing unusual. It’s just that my family seems to think that once the surgery is over, everything goes back to normal and they no longer showed concern to me.” (P16, aged 37, non-lymphedema).

“Ideally, the doctors should have provided some guidance and instructions, but they didn’t say anything or provide any information. If the doctors had explicitly told us not to do dangerous behaviors, we definitely wouldn’t dare to do them. But they never mentioned it.” (P12, aged 42, lymphedema).

Domain 4: Other barriers

In addition to the constructs of the ITHBC, other barriers were inducted from interviews. Limited treatment resource for lymphedema ($n = 1$) was complained by one participant. Two participants described that lymphedema management can be inconvenient ($n = 2$), especially for those with lymphedema who received CDT. “*During this period of wearing bandages, it’s not convenient to use a leather belt like that. It’s not easy to fasten, and even pulling up*

my pants with multiple layers becomes quite a struggle. It's just not convenient at all." (P1, aged 67, lymphedema) One young participant said that self-management practices, such as exercise and lymph self-drainage, were boring and tedious to adhere to ($n = 1$). *"I just feel that doing this lymph drainage for such a long time is time-consuming and quite bothersome, so I'm not really keen on doing it."* (P8, aged 35, non-lymphedema).

Discussion

This study employed a theory-based qualitative approach to examine and classify breast cancer survivors' experiences of lymphedema self-management and their reasons for adhering or not adhering to LSMB. Using both deductive and inductive coding methods, several barriers and facilitators were identified and presented according to the framework of ITHBC, including knowledge and belief, self-regulation skills and ability, social facilitation, as well as other barriers. The findings of our study are largely in line with existing literature, indicating that breast cancer survivors experience multiple factors related to knowledge and belief, self-regulation skill and ability, and social facilitation, which have an impact on their LSMB.

"*Knowledge and belief*" is the first construct of the ITHBC framework. Our findings confirmed the results of previous study regarding the role of knowledge in enhancing LSMB in breast cancer survivors [11, 15, 17]. During the interview, some participants expressed that they did not receive any information about lymphedema, and attributed their failure in lymphedema management to the lack of knowledge [32]. It is challenging to confirm whether they actually received lymphedema information or not. Commonly, providing preoperative or postoperative lymphedema education to breast cancer survivors has been included as a routine in clinical practice. However, many patients were still in the stress phase of breast cancer diagnosis or surgery, or they perceived that lymphedema was not relevant to them, resulting in a limited understanding of the knowledge. Currently, various lymphedema education resources and methods are available, such as face-to-face health education, brochures, leaflets, and online education resources. However, additional information may not always be the solution for the obstacle of insufficient knowledge. Uhlmann et al.'s study revealed that while 72% of breast cancer survivors recalled receiving lymphedema education, their knowledge about lymphedema was limited, with < 25% of the respondents answering > 50% of the risk factor questions correctly [33]. We consider that the timing of education to be of utmost importance. Researchers recommended providing consistent education at different timepoints (e.g., at pre-/post-surgery,

chemotherapy, radiation therapy, and survivorship visits) throughout breast cancer survivors' survivorship to ensure understanding [33].

The effectiveness of education cannot be ensured solely through one-way knowledge provision. One patient shared that despite receiving a substantial amount of information, she disregarded much of it due to feeling overwhelmed and believed that knowing too much would make her feel stressed and anxious. It can be seen that survivors' health beliefs regarding lymphedema are also crucial. Here in the ITHBC, health beliefs refer to *personal perceptions, self-efficacy, outcome expectancy, and goal congruence* [24]. Regarding *personal perceptions*, we found that participants who perceived enough threats and negative impacts of lymphedema, the importance and benefits of lymphedema management, were more like to engage in better lymphedema self-management, while those with insufficient perception of lymphedema threats and importance of lymphedema self-management showed poor performance. Based on the interviews, we observed that participants who have witnessed cases of lymphedema or who have experienced lymphedema themselves have a heightened perception of threats posed by lymphedema, and they performed better lymphedema self-management. These findings can be also explained by the Health Belief Model [34]. Additionally, since lymphedema is a chronic condition that may not present immediate danger, survivors often failed to fully recognize its potential threats and severity. This finding was evident in our study. Hence, we recommend healthcare professionals to incorporate specific cases of lymphedema into health education, or invite survivors with lymphedema to participate in peer health education activities, so as to enhance their awareness and understanding of lymphedema [20, 32].

In addition, patients' perceptions of *self-efficacy* are also contributing factors to adherence to lymphedema self-management. Previous research, both qualitative and quantitative, consistently indicated a significant correlation between decreased self-efficacy and poor LSMB [11, 14, 15, 18, 35, 36]. This was also echoed by participants in our interviews, with one participant expressing, "*I feel like it's really hard for me to manage it*". Individuals with poorer self-efficacy are less likely to engage in self-management behaviors, such as wearing compression garments, practicing therapeutic exercises, and seeking professional assistance when needed. Self-efficacy enhancing strategies can be developed based on the four sources of influences, including mastery experiences, vicarious learning, social persuasion, and emotional states [37]. For example, making small goals and using self-management diaries to make individual's efforts and progress visible, applying the illustrative impact of positive experiences and stories of successful self-management cases, giving positive feedbacks and verbal encouragement by healthcare providers and family members, and strategies

to relieve stress or negative emotions associated with LSMB [20, 37].

To our knowledge, *outcome expectancy* and *goal congruence* have not previously been studied in lymphedema management of breast cancer survivors. *Outcome expectancy*, defined as the belief that engaging in a behavior will result in desired outcomes [24], plays a crucial role in shaping LSMB. We noted that participants with higher outcome expectancy, who strongly believed that their efforts would lead to improved outcomes, were more likely to engage in proactive LSMB, such as regular exercise, limb protection, and adherence to lymphedema management routines. This finding aligns with recent study by Karl et al. (2022) [38], which demonstrated a positive association between outcome expectancy and adherence to self-management practices in patients with type 2 diabetes. Conversely, patients with lower outcome expectancy tended to demonstrate suboptimal self-management behaviors. As lymphedema self-management is a long-term and slow-acting process, it might be common to see that patients' outcome expectancy decreased over time, especially when there is no noticeable effect. We saw such cases in our interview. These findings highlight the significance of addressing and sustaining outcome expectancy during the lymphedema self-management journey. Strategies such as regular reinforcement of positive outcomes, peer support networks, and tailored education on realistic outcome expectations are recommended [39]. Moreover, it is important for healthcare professionals to address any misconceptions or concerns that breast cancer survivors may have regarding the effectiveness of LSMB [40].

In this study, *goal congruence* could be understood as the extent to which patients can handle competing or conflicting demands in a coordinated and consistent manner to achieve their ultimate goals—LSMB [24]. The achievement of individuals' goals regarding their health condition contributes to enhanced LSMB and improved outcomes. In the original conception of the ITHBC, goal congruence was considered a component of health beliefs [24]. Later, Ryan's subsequent research indicated that goal congruence also fitted better under the self-regulation dimension [41]. In our study, we consider goal congruence as both a health belief and the self-regulation strategies adopted to achieve the health goals. During the interview, some participants put their own health and the management of lymphedema at the first before family and career. Yet, some other survivors struggled between prioritizing lymphedema management and family/social responsibilities, which hindered them to engage in lymphedema self-management activities. Some studies on self-management behaviors (e.g., Calcium and Vitamin D Intake, physical activity, and dietary, etc.) incorporated strategies targeted on enhancing goal congruence and achieved effective outcomes [28, 42]. For breast cancer survivors who exhibit limited goal congruence in

lymphedema self-management, implementing specific strategies, such as helping women recognize conflicting goals (such as exercise and limb protection) and providing practical advice and reframing techniques to reduce the dissonance between these goals (e.g., wearing gloves to protect the limbs while doing household chores), can be beneficial.

Social facilitation includes social influence and social support [24]. Our findings indicate that breast cancer survivors experienced both positive and negative social influence, primarily from their peer patients and medical staffs. This is the first report of such results in published literature. Misconceptions and poor self-management behaviors related to lymphedema among peer patients can directly influence the self-management motivation and behaviors of breast cancer survivors. This once again emphasizes the importance of patient education and self-management enhancing interventions. Moreover, some healthcare professionals with insufficient knowledge about lymphedema management may misguide survivors by asserting that there are no effective methods to manage lymphedema. Similar results can be found in existing studies [18, 43]. Education about lymphedema among relevant healthcare providers is warranted to improve BCRL care [44]. Lacking of social support has been repeatedly reported as a significant barrier to LSMB [11, 16, 18]. Some participants experienced a lack of emotional support from family and colleagues, instrumental support (mostly household chores), and professional information support from health-care providers. Based on the definition, it is evident that successful self-management requires collaboration with the social network and health-care provider(s). Given the well-established role of social support and the maturity of existing intervention strategies aimed at enhancing it, here we will not discuss about specific intervention suggestions. Our main emphasis is on enhancing awareness about the importance of social networks in providing social support. To address this issue, conducting public awareness campaigns and educating the public about lymphedema is essential [32]. By increasing knowledge and understanding of breast cancer related-lymphedema, we can encourage active involvement and support from survivors' social networks.

Self-regulation is a dynamic process employed by individuals as they incorporate behavior change into daily routines and lifestyles. It encompasses a range of activities such as goal setting, self-monitoring and reflective thinking, decision making, planning and plan enactment, self-evaluation, and management of emotions occurring with the behavior change [24]. In this study, majority of participants learned and developed their own self-regulation skills and abilities during the process of lymphedema self-management, such as incorporating manual lymph drainage into daily routine, lifting heavy objects with contralateral arm. Sherman et al. (2015) investigated the correlation between

self-regulation ability to manage distress and adherence to lymphedema self-management, revealing a positive association [15]. As expected, survivors with poor LSMB were more likely to report poor self-regulation skills and abilities. Our prior quantitative research showed that self-regulation acted as a key moderator, between knowledge, illness perception, self-efficacy, social support and lymphedema self-management, suggesting that interventions targeting self-regulation may yield greater effectiveness [16]. Recent literature also highlighted the effectiveness of interventions that focus on enhancing self-regulation skills to promote self-management behaviors of chronic disease [42]. For lymphedema management of breast cancer survivors, tailored interventions involving providing knowledge and skills for self-monitoring, goal setting, informed decision-making, and self-evaluation can be implemented. Besides, peer support and counseling sessions can also contribute to building self-regulation skills through emotional support and shared experiences. By addressing barriers, providing knowledge, fostering self-efficacy, increasing self-regulation skills, and providing supportive interventions, healthcare providers can empower breast cancer survivors to overcome challenges, successfully self-manage lymphedema, and improve their overall well-being. However, further research is needed in the area.

Regarding other barriers, *limited treatment resources* was identified as the significant challenge one. In a previous qualitative study, Zhao et al. (2021) categorized the availability and accessibility of medical resources to lack of social support. According to the ITHBC, social support was defined as emotional, instrumental, or informational support [24]. Therefore, we classified this theme into other barriers, instead of social support. In China, there is still a shortage of lymphedema clinics and lymphedema therapists [45]. Limited availability of healthcare professionals with expertise in lymphedema, inadequate access to lymphedema clinics or rehabilitation centers, and insufficient insurance coverage for lymphedema-related services contribute to this barrier [20]. To address this barrier, efforts should be directed towards increasing government and public awareness of lymphedema, development of specialized lymphedema clinics, training programs for healthcare professionals, etc. [20]. Lymphedema self-management is often characterized as long-term, repetitive, burdensome, inconvenient and tedious, which leads to a sense of frustration for survivors and poses significant challenges to survivors' adherence [11]. Furthermore, some management practices are physically uncomfortable or restrictive, such as wearing compression garments [11]. Apart from educating on the importance and benefits of self-management, healthcare providers can offer practical tips and strategies to help survivors incorporate management practices into their daily lives in a more convenient and enjoyable manner. Additionally, recognizing the inconvenient and boring aspects of lymphedema

management practices is essential for developing interventions and support programs. Further efforts are also needed to explore more comfortable and effective lymphedema management strategies.

Limitations

Though our study offers insight to the understanding of LSMB in breast cancer survivors, it is subject to several limitations. The first limitation is that this study was conducted on a limited number of participants from one center, although efforts were made to achieve a reasonably diverse group (e.g., different ages, surgery types, lymphedema status, self-management behaviors) and ensure data saturation. Like many qualitative studies, it is important to consider that our findings may be context-specific to the particular setting, population, or time period the study conducted, and may not be widely applicable or generalizable. The second limitation is that we did not return the transcribed interview files to the study participants for verification and confirmation, which may have introduced some bias due to the inability to ensure the accuracy of the transcriptions. Another limitation is that the application of both deductive and inductive coding approaches yielded a substantial number of themes; some of them were supported by only a small number of extracts. Future qualitative studies exploring the barriers and facilitators of LSMB would contribute to expanding our understanding in this area.

Conclusion

By utilizing constructs from a theory-based health behavior change framework—the ITHBC, this study offers valuable insights into the barriers, facilitators, and cues to action among breast cancer survivors for engaging in LSMB. Essential constructs, including lymphedema knowledge, self-efficacy, personal perception, goal congruence, outcome expectancy, self-regulation ability and skills, social support and social influence, emerged as influential factors that could either facilitate or hinder lymphedema self-management. Additionally, other barriers such as limited treatment resources and the inconvenience of lymphedema self-management were identified. The findings can support future efforts towards targeted lymphedema self-management behavior change. Healthcare providers and policy-makers can apply these findings to develop more effective interventions and policies to support breast cancer survivors in their efforts to manage lymphedema.

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Data availability The datasets generated and/or analyzed in this study are not publicly accessible due to privacy concerns but are available from the corresponding author on reasonable request.

Declarations

Ethics approval This study was approved by the Biomedical Ethics Committee of Peking University (Approval number: IRB 00001052–21123) prior to the commencement.

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

Competing interests The authors declare no competing interests.

References

- Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, 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(3):209–49. <https://doi.org/10.3322/caac.21660>.
- Shen A, Lu Q, Fu X, Wei X, Zhang L, Bian J, et al. Risk factors of unilateral breast cancer-related lymphedema: an updated systematic review and meta-analysis of 84 cohort studies. *Support Care Cancer*. 2022;31(1):18. <https://doi.org/10.1007/s00520-022-07508-2>.
- Donahue PMC, MacKenzie A, Filipovic A, Koelmeyer L. Advances in the prevention and treatment of breast cancer-related lymphedema. *Breast Cancer Res Treat*. 2023. <https://doi.org/10.1007/s10549-023-06947-7>.
- Armer JM, Ostby PL, Ginex PK, Beck M, Deng J, Fu MR, et al. ONS guidelines for cancer treatment-related lymphedema. *Oncol Nurs Forum*. 2020;47(5):518–38. <https://doi.org/10.1188/20.ONF.518-538>.
- Eaton LH, Narkthong N, Hulett JM. Psychosocial issues associated with breast cancer-related lymphedema: a literature review. *Curr Breast Cancer Rep*. 2020;12(4):216–24. <https://doi.org/10.1007/s12609-020-00376-x>.
- Anderson EA, Anbari AB, Sun Y, Armer JM. A multiple case study of Latina breast cancer survivors returning to work with breast cancer-related lymphedema: adaptation, resilience, and quality of life. *Hisp Health Care Int*. 2022;20(4):222–30. <https://doi.org/10.1177/15404153221116755>.
- Van de Velde D, De Zutter F, Satink T, Costa U, Janquart S, Senn D, et al. Delineating the concept of self-management in chronic conditions: a concept analysis. *BMJ Open*. 2019;9(7):e027775. <https://doi.org/10.1136/bmjopen-2018-027775>.
- Liu F, Li F, Fu MR, Zhao Q, Wang Y, Pang D, et al. Self-management strategies for risk reduction of subclinical and mild stage of breast cancer-related lymphedema: a longitudinal, quasi-experimental study. *Cancer Nurs*. 2021;44(6):E493–502. <https://doi.org/10.1097/NCC.0000000000000919>.
- Damstra RJ, Halk AB. Dutch Working Group on L. The Dutch lymphedema guidelines based on the International Classification of Functioning, Disability, and Health and the chronic care model. *J Vasc Surg Venous Lymphat Disord*. 2017;5(5):756–65. <https://doi.org/10.1016/j.jvsv.2017.04.012>.
- Davies C, Levenhagen K, Ryans K, Perdomo M, Gilchrist L. Interventions for breast cancer-related lymphedema: clinical practice guideline from the academy of oncologic physical therapy of APTA. *Phys Ther*. 2020;100(7):1163–79. <https://doi.org/10.1093/ptj/pzaa087>.
- Fu X, Lu Q, Pang D, Shen A, Shih YA, Wei X. Experiences of breast cancer survivors with lymphedema self-management: a systematic review of qualitative studies. *J Cancer Surviv*. 2022. <https://doi.org/10.1007/s11764-022-01225-9>.
- Alcorso J, Sherman KA, Koelmeyer L, Mackie H, Boyages J. Psychosocial factors associated with adherence for self-management behaviors in women with breast cancer-related lymphedema. *Support Care Cancer*. 2016;24(1):139–46. <https://doi.org/10.1007/s00520-015-2766-x>.
- Deveci Z, Karayurt O, Eyigor S. Self-care practices, patient education in women with breast cancer-related lymphedema. *Turk J Phys Med Rehabil*. 2021;67(2):187–95. <https://doi.org/10.5606/tftrd.2021.5022>.
- Brown JC, Cheville AL, Tchou JC, Harris SR, Schmitz KH. Prescription and adherence to lymphedema self-care modalities among women with breast cancer-related lymphedema. *Support Care Cancer*. 2014;22(1):135–43. <https://doi.org/10.1007/s00520-013-1962-9>.
- Sherman KA, Miller SM, Roussi P, Taylor A. Factors predicting adherence to risk management behaviors of women at increased risk for developing lymphedema. *Support Care Cancer*. 2015;23(1):61–9. <https://doi.org/10.1007/s00520-014-2321-1>.
- Shen A, Wu P, Qiang W, Fu X, Wang F, Zhu F, et al. Predicting lymphedema self-management behaviours in breast cancer patients: a structural equation model with the Integrated Theory of Health Behaviour Change. *J Adv Nurs*. 2023. <https://doi.org/10.1111/jan.15759>.
- Jeffs E, Ream E, Shewbridge A, Cowan-Dickie S, Crawshaw D, Huit M, et al. Exploring patient perception of success and benefit in self-management of breast cancer-related arm lymphoedema. *Eur J Oncol Nurs*. 2016;20:173–83. <https://doi.org/10.1016/j.ejon.2015.08.001>.
- Ostby PL, Armer JM, Smith K, Stewart BR. Patient perceptions of barriers to self-management of breast cancer-related lymphedema. *West J Nurs Res*. 2018;40(12):1800–17. <https://doi.org/10.1177/0193945917744351>.
- Ridner SH, Rhoten BA, Radina ME, Adair M, Bush-Foster S, Sinclair V. Breast cancer survivors' perspectives of critical lymphedema self-care support needs. *Support Care Cancer*. 2016;24(6):2743–50. <https://doi.org/10.1007/s00520-016-3089-2>.
- Zhao H, Wu Y, Zhou C, Li W, Li X, Chen L. Breast cancer-related lymphedema patient and healthcare professional experiences in

- lymphedema self-management: a qualitative study. *Support Care Cancer*. 2021;29(12):8027–44. <https://doi.org/10.1007/s00520-021-06390-8>.
21. Govender R, Wood CE, Taylor SA, Smith CH, Barratt H, Gardner B. Patient experiences of swallowing exercises after head and neck cancer: a qualitative study examining barriers and facilitators using behaviour change theory. *Dysphagia*. 2017;32(4):559–69. <https://doi.org/10.1007/s00455-017-9799-x>.
 22. Young M, Varpio L, Uijtdehaage S, Paradis E. The spectrum of inductive and deductive research approaches using quantitative and qualitative data. *Acad Med*. 2020;95(7):1122. <https://doi.org/10.1097/ACM.00000000000003101>.
 23. Davis R, Campbell R, Hildon Z, Hobbs L, Michie S. Theories of behaviour and behaviour change across the social and behavioural sciences: a scoping review. *Health Psychol Rev*. 2015;9(3):323–44. <https://doi.org/10.1080/17437199.2014.941722>.
 24. Ryan P. Integrated Theory of Health Behavior Change: background and intervention development. *Clin Nurse Spec*. 2009;23(3):161–70; quiz 71–2. <https://doi.org/10.1097/NUR.0b013e3181a42373>
 25. Bao Y, Wang C, Xu H, Lai Y, Yan Y, Ma Y, et al. Effects of an mHealth intervention for pulmonary tuberculosis self-management based on the integrated theory of health behavior change: randomized controlled trial. *JMIR Public Health Surveill*. 2022;8(7):e34277. <https://doi.org/10.2196/34277>.
 26. Ohlendorf JM, Weiss ME, Oswald D. Predictors of engagement in postpartum weight self-management behaviours in the first 12 weeks after birth. *J Adv Nurs*. 2015;71(8):1833–46. <https://doi.org/10.1111/jan.12640>.
 27. Rao D, Stevenson B, Shiyabola OO. Using the integrated theory of health behavior change to assess factors affecting diabetes medication adherence among black adults during COVID-19: an explanatory sequential mixed methods design. *Ethn Health*. 2023;28(7):983–1005. <https://doi.org/10.1080/13557858.2023.2198683>.
 28. Ryan P, Maierle D, Csuka ME, Thomson A, Szabo A. Computer-based intervention to enhance self-management of calcium and vitamin D intake in women. *West J Nurs Res*. 2013;35(8):986–1010. <https://doi.org/10.1177/0193945913483369>.
 29. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–57. <https://doi.org/10.1093/intqhc/mzm042>.
 30. Francis JJ, Johnston M, Robertson C, Glidewell L, Entwistle V, Eccles MP, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychol Health*. 2010;25(10):1229–45. <https://doi.org/10.1080/08870440903194015>.
 31. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–88. <https://doi.org/10.1177/1049732305276687>.
 32. Buki LP, Rivera-Ramos ZA, Kanagui-Munoz M, Heppner PP, Ojeda L, Leahardy EN, et al. “I never heard anything about it”: Knowledge and psychosocial needs of Latina breast cancer survivors with lymphedema. *Womens Health*. 2021;17:Art n 7455065211002488. <https://doi.org/10.1177/17455065211002488>.
 33. Uhlmann RA, Mott SL, Curry M, Phadke S, Sugg SL, Erdahl LM, et al. Analysis of the understanding and worry about lymphedema of patients with breast cancer. *Ann Surg Oncol*. 2022;29(10):6428–37. <https://doi.org/10.1245/s10434-022-12189-6>.
 34. Janz NK, Becker MH. The health belief model—a decade later. *Health Educ Quart*. 1984;11(1):1–47. <https://doi.org/10.1177/109019818401100101>.
 35. Ostby PL, Armer JM. Complexities of adherence and post-cancer lymphedema management. *J Pers Med*. 2015;5(4):370–88. <https://doi.org/10.3390/jpm5040370>.
 36. Jiang WT, Chen LJ. Analysis of the factors and moderating role of self-care ability among patients with breast cancer-related lymphedema. *J Clin Nurs*. 2023;32(5–6):926–40. <https://doi.org/10.1111/jocn.16495>.
 37. Lee LL, Arthur A, Avis M. Using self-efficacy theory to develop interventions that help older people overcome psychological barriers to physical activity: a discussion paper. *Int J Nurs Stud*. 2008;45(11):1690–9. <https://doi.org/10.1016/j.ijnurstu.2008.02.012>.
 38. Karl FM, Holle R, Schwettmann L, Peters A, Laxy M. Time preference, outcome expectancy, and self-management in patients with type 2 diabetes. *Patient Prefer Adher*. 2018;12:1937–45. <https://doi.org/10.2147/Ppa.S175045>.
 39. Omid Z, Kheirkhah M, Abolghasemi J, Haghight S. Effect of lymphedema self-management group-based education compared with social network-based education on quality of life and fear of cancer recurrence in women with breast cancer: a randomized controlled clinical trial. *Qual Life Res*. 2020;29(7):1789–800. <https://doi.org/10.1007/s11136-020-02455-z>.
 40. Anderson EA, Armer JM. Factors impacting management of breast cancer-related lymphedema (BCRL) in Hispanic/Latina breast cancer survivors: a literature review. *Hisp Health Care Int*. 2021;19(3):190–202. <https://doi.org/10.1177/1540415321990621>.
 41. Ryan P, Weiss M, Traxel N, Brondino M. Testing the Integrated Theory of Health Behaviour Change for postpartum weight management. *J Adv Nur*. 2011;67(9):2047–59. <https://doi.org/10.1111/j.1365-2648.2011.05648.x>.
 42. Taani MH, Strath SJ, Schiffman R, Fendrich M, Harley A, Cho CC, et al. Self-management processes, sedentary behavior, physical activity and dietary self-management behaviors: impact on muscle outcomes in continuing care retirement community residents. *BMC Geriatr*. 2022;22(1):48. <https://doi.org/10.1186/s12877-021-02691-z>.
 43. Yaman A, Borman P, Ozdemir O, Umaroglu MM. Clinical awareness and knowledge of breast cancer-related lymphedema among a group of psychiatrists in Turkey—an online survey. *Niger J Clin Pract*. 2022;25(10):1654–9. https://doi.org/10.4103/njcp.njcp_1698_21.
 44. Yarmohammadi H, Rooddehghan A, Soltanipur M, Sarafraz A, Anari SFM. Healthcare practitioners’ knowledge of lymphedema. *Int J Vasc Med*. 2021;2021:3806150. <https://doi.org/10.1155/2021/3806150>.
 45. Wu PP, Qiang WM, Wang Y, Shen AM. Analysis on the status quo of lymphedema nursing clinics in 60 hospitals. *Chin J Pract Nurs*. 2022;38(17):1331–6. <https://doi.org/10.3760/cma.j.cn211501-20211115-03130>.

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