



Experiences of breast cancer survivors with lymphedema self-management: a systematic review of qualitative studies

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Abstract

Purpose This study systematically identified, evaluated, and synthesized qualitative literature on the experiences of breast cancer survivors with lymphedema self-management.

Methods This systematic review followed the Joanna Briggs Institute meta-aggregation approach and was guided by the ENTREQ, graded according to the ConQual approach, and evaluated using the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). Qualitative studies related to the experiences in lymphedema self-management among breast cancer survivors conducted until March 9, 2022, were searched. The selected studies were reviewed independently, and the data were synthesized collaboratively into core themes.

Results A total of 24 studies were included, and 85 findings resulted in three synthesis findings: (a) breast cancer survivors face challenges in lymphedema self-management, (b) breast cancer survivors are entangled in rebuilding a new balance between different roles, and (c) breast cancer survivors seek internal and external resources to regulate negative emotions.

Conclusions Lymphedema self-management is a lifetime commitment and a challenge for breast cancer survivors, who find it difficult to adhere to self-management and cope with their problems. They require timely and continuous effective self-management education, and instrumental and emotional support from others, particularly healthcare providers and family members.

Implications for cancer survivors Timely self-management education and access to lymphedema treatment and related resources are important for survivors to prevent and manage lymphedema. Breast cancer survivors should develop coping skills, and family members should participate in survivors' lymphedema self-management.

Keywords Lymphedema · Breast cancer survivors · Self-management · Meta-aggregation · Qualitative studies

Introduction

Breast cancer is the most common cancer, with an estimated 2.3 million new cases in 2020 and a 5-year prevalence of 7.8 million cases worldwide [1]. The 5-year relative survival rate for breast cancer is approximately 90% [2], and, with breast cancer survivors living longer, their quality of life must be prioritized.

Breast cancer-related lymphedema is a common complication of breast cancer treatment, with an incidence ranging from 3 to 36.7% [3] and is mainly presented as progressive swelling of the upper limbs [4]. Lymphedema has

various negative physical and psychosocial effects, including decreased mobility and function, disfigurement, emotional problems, and poor quality of life [4]. Lymphedema is an incurable and lifelong threat to breast cancer survivors.

The International Society of Lymphology (ISL) 2020 Consensus stressed the importance of timely prevention and management by tertiary prevention of lymphedema: primary prevention to avoid lymphedema before its onset, secondary prevention for treatment at an early stage, and tertiary prevention for treatment at the late stage [5]. Self-management plays a key role in the prevention and control of lymphedema [6]. Self-management is defined as “the intrinsically controlled ability of an active, responsible, informed, and autonomous individual to live with the medical, role, and emotional consequences of one’s chronic condition(s) in partnership with the social network and health-care provider(s),” including medical, emotional, and role

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management [7]. To prevent the occurrence and progression of lymphedema, breast cancer survivors should engage in timely and lifelong self-management [6]. However, previous studies have reported poor adherence to lymphedema self-management [8, 9], which is why understanding how patients truly feel and experience lymphedema self-management is the first step toward improving their performance. Several qualitative studies have explored the experiences of survivors in lymphedema self-management [10–12]. Burckhardt et al. [13] described the experiences of female patients with lymphedema. Ridner et al. [14] summarized ten categories of self-management activities and evaluated their level of evidence. Dwarswaard et al. [15] identified the need for self-management support from the perspective of patients with chronic conditions. However, these studies did not reveal how breast cancer survivors experience lymphedema self-management.

Aims

This qualitative systematic review aimed to consolidate the existing evidence regarding lymphedema self-management of breast cancer survivors, which could enhance the understanding of health-care providers and allow them to provide adequate patient-centered self-management support.

Methods

The qualitative systematic study followed the meta-aggregation approach of the Joanna Briggs Institute [16]. The study protocol was registered in PROSPERO and conducted using the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) checklist [17] (Online Resource 1).

Search methods

A three-step search strategy was used [16]. Initially, we searched PubMed and CINAHL and analyzed the text words contained in the title, abstract, and index terms used to describe lymphedema self-management. Then, the second search using medical subject headings (MeSH), terms, and free-text keywords was performed across PubMed, Web of Science, Embase, CINAHL, PsycINFO, and Cochrane from inception to March 9, 2022, and was limited to the English language. As the concept of self-management lacked clarity, this study did not use search terms related to self-management but those related to “breast cancer-related lymphedema” and “qualitative research.” The search strategy for each database is shown in Online Resource 2. After the second-step search, the studies

were screened according to eligibility criteria. Finally, we searched the reference lists of all included articles for additional studies.

Eligibility criteria

Participants Individuals aged ≥ 18 years who were diagnosed with any stage of breast cancer were included, without restriction on the diagnosis of lymphedema. Studies were included when breast cancer survivors had participated in lymphedema self-management, along with the prevention and management of lymphedema. Participants with primary lymphedema and other types of secondary lymphedema (except breast cancer-related lymphedema) were excluded. Moreover, studies of different types of lymphedema but no reporting data about breast cancer-related lymphedema in particular were excluded.

Phenomena of interest This study explored lymphedema self-management in patients with breast cancer. Lymphedema self-management refers to the intrinsically controlled ability of an active, responsible, informed, and autonomous individual to live with the medical, role, and emotional consequences of lymphedema in partnership with social networks and health-care providers [7]. Studies that only explored how lymphedema affected patients’ lives but did not describe how breast cancer survivors dealt with lymphedema were excluded.

Context Patients with breast cancer need to implement long-term self-management during survival. This review considered studies conducted in all settings (e.g., home, primary care settings, hospitals, and rehabilitation centers).

Types of studies This review included qualitative studies but is not limited to those that used designs such as phenomenology, grounded theory, ethnography, and hermeneutics. Mixed-method studies and dissertations were included when there was a separate report in the qualitative data, and only those published in English. Abstracts with no comprehensive description of findings were excluded.

Quality appraisal

The quality of the studies was evaluated using the standard Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research (JBI-QARI) [16]. Two independent reviewers assessed methodological quality, and disagreements were resolved through discussion or by a third reviewer. A predetermined minimum of “yes” responses for six items is required for inclusion.

Data extraction and synthesis

Two independent reviewers extracted qualitative data using Microsoft Excel 2019 (Table 1). The findings were extracted by a primary reviewer and confirmed by a secondary reviewer. The principle of extraction is to maintain the same level of extraction within a certain article, themes, subthemes, or the authors' rich descriptions under themes. Moreover, two reviewers assigned credibility to each finding—unequivocal, credible, and unsupported (Online Resource 3).

Qualitative research findings were synthesized using a meta-aggregation approach. Two researchers categorized these findings based on similarities in their meanings. Only unequivocal and credible findings were included in this aggregation. These categories were then aggregated to produce a single comprehensive set of synthesized findings, and each synthesized finding was graded according to the ConQual approach [16].

Results

Search outcomes

As shown in the PRISMA flow diagram, the initial electronic database search resulted in 1163 articles, 599 of which were duplicates and thus removed (Fig. 1) [18]. The authors excluded 512 citations after screening the titles and abstracts according to the eligibility criteria, and the remaining 52 studies were included. However, eight of the selected studies did not have a full text. After careful examination of the 44 studies with full texts, 20 were excluded and 24 included.

Characteristics of studies

Table 1 presents the characteristics of the studies. The 24 studies were published between 2001 and 2021 and were located in Australia ($n=2$), China ($n=1$), the USA ($n=15$), Turkey ($n=2$), Japan ($n=2$), Canada ($n=1$), and Sweden ($n=1$). They had various interests, including the experience of living with breast cancer-related lymphedema ($n=9$), self-management lymphedema ($n=10$), perspectives on self-management support, and support needs ($n=5$).

Methodological quality

The JBI-QARI quality assessment of the 24 studies is reported in Online Resource 4 [16], and all of them scored between 7 and 9 on the 10 questions. However, most studies did not perform well in three questions (Q1, Q6, and Q7). Four studies showed a strong correlation between

methodological and philosophical approaches, five studies located the researcher, either culturally or theoretically, and only one addressed the influence of the researcher.

Findings of the review

In the 24 included studies [10–12, 19–39], 85 findings were identified and classified as unequivocal (76) and credible (9) (Table 2). They were aggregated into eight categories based on similar meanings and three synthesized findings, and the final synthesized findings were graded according to the ConQual summary of the findings, as shown in Table 3.

Synthesized finding 1: breast cancer survivors face challenges in lymphedema self-management

Breast cancer survivors have a long road to lymphedema self-management and encounter different challenges at different stages of the disease. There are four types of situations in lymphedema self-management: insufficient and conflicting information, a hard road to treatment, poor adherence to self-preservation, and problem-focused coping.

Category 1: insufficient and conflicting information Most breast cancer survivors lacked knowledge of lymphedema self-management [10] and were unaware that lymphedema was a complication [28]. There was limited access to lymphedema knowledge; however, most breast cancer survivors rarely requested more education because they perceived that healthcare professionals were too busy [21]. Some received inaccurate and inappropriate information that did not meet their needs [21]. They attempted to find information from the Internet by trial-and-error attempts or through incidental discovery via social networking [34]. However, the information they searched for was fragmented and insufficient to help them with self-management. Additionally, some survivors are aware of the dangers of swelling, but they often fail to remember this information because of severe distress or insufficient understanding of cancer diagnosis [29]. Overall, survivors received inadequate and delayed education on lymphedema self-management. A lack of education has reduced breast cancer survivors' confidence in monitoring and managing lymphedema on their own [21], and they yearned for timely education and instruction [10], "Um, one question that I have had is so how long do I continue with these exercises, you keep doing it forever? But no one answered that question, I don't actually know? There sort of not a lot of long term follow through" [21].

Category 2: a hard road to treatment Breast cancer survivors believed that the most challenging experience with lymphedema was the struggle at the beginning when they

Table 1 Summary of included studies

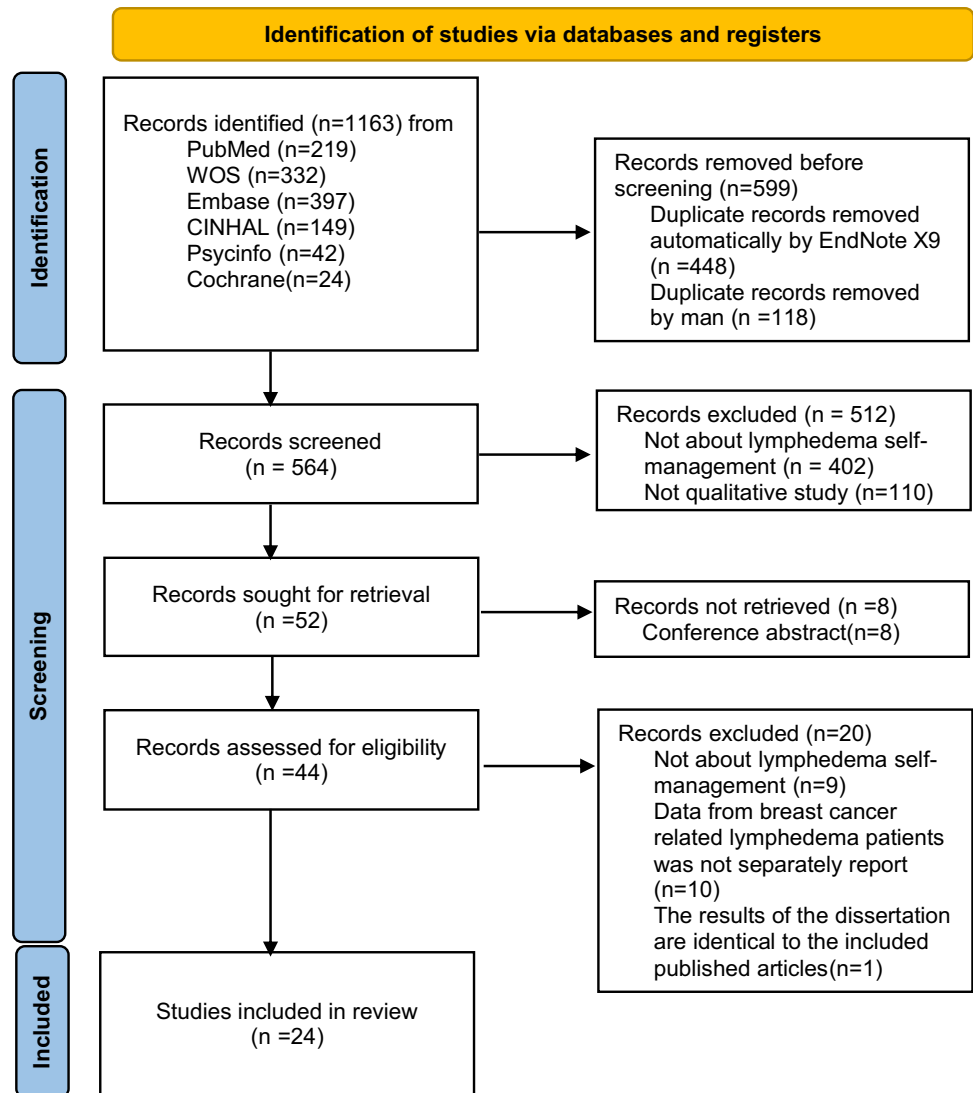
Author, year	Country	Phenomena of interest	Age (years)	Ratio of participants with lymphedema	Methods for data collection and analysis	JBI-QARI overall score
Armer et al., 2011	USA	Limitations of self-care, as identified by Orem, in breast cancer survivors in performing specific self-care actions to meet the therapeutic self-care demands related to reducing the risk of lymphedema	M = 60	0/14	Open-ended questionnaire, template analysis	7
Ayşe et al., 2021	Turkey	The lived experiences for supportive care needs of women with lymphedema	M = 52.15, SD = 7.69	19/19	Semi-structured interview, thematic analysis	7
Buki et al., 2021	USA	The lived experiences of Latina women with lymphedema	M = 52.6, SD = 9.65, Range = 40–68	10/10	Semi-structured interviews, thematic analysis and constant comparison methodology	7
Cal and Bahar, 2016	Turkey	Women's barriers to prevention of lymphedema after breast surgery and home care needs	M = 57.5, Range = 42–75	14/14	Semi-structured in-depth interviews, inductive content analysis	7
Fu, 2005	USA	The experience of managing lymphedema in breast cancer survivors	Range = 46–74	12/12	Semi-structured interview, reflective and intuitive, Giorgi analysis	8
Fu, 2010	USA	Breast cancer survivors' experiences of managing lymphoedema and effective strategies for managing lymphoedema and any potential barriers	-	34/34	In-depth interview, descriptive data analysis method with intuitive reflections	8
Fu, M. R., 2008	USA	The experience of work of breast cancer survivors with lymphoedema	M = 53, Range = 42–65	22/22	Semi-structured interview, reflective and intuitive, Giorgi analysis	8
Greenslade and House, 2006	Canada	The physical and psychosocial suffering that women with lymphedema experienced	M = 63, Range = 45–82	13/13	Semi-structured interviews, thematic analysis	7
Heppner et al., 2009	USA	The stressors associated with lymphedema, how women cope with the stressors, and the role of social support	M = 58.6, Range = 47–88	10/10	In-depth interviews, consensual qualitative research approach	8
Hurren and Yates, 2019	Australia	The satisfaction with reference to the type of information provided, appropriateness of clinical information and timeliness of information at the specific stage of their illness trajectory	Range = 31–55	2/11	Semi-structured interview, inductive thematic analysis	7
Johansson et al., 2003	Sweden	Women's experiences of light or moderate arm lymphoedema following breast cancer treatment	Range = 44–59	12/12	Semi-structured interview, phenomenological approach	7
Koelmeyer et al., 2021	Australia	Understanding of attitudes towards lymphoedema home monitoring using BIS	M = 60.77, Range = 42–75	24/31	Focus groups interview, thematic analysis	8
Kozak et al., 2020	USA	The lymphedema management experience of weight patients	M = 63.2	26/26	Focus group, grounded theory and constant comparative method	7

Table 1 (continued)

Author, year	Country	Phenomena of interest	Age (years)	Ratio of participants with lymphedema	Methods for data collection and analysis	JBI-QARI overall score
Radina and Armer, 2001	USA	Issues related to coping with lymphedema within the context of family roles and responsibilities and family functioning	-	6/6	In-depth interviews, ethnographic approach	7
Radina and Armer, 2004	USA	The quality-of-life experiences of lymphedema women within the context of their family and social roles	-	6/6	In-depth interviews and focus group interviews, template analysis	9
Radina et al., 2014	USA	The essential capabilities to engage in self-care actions related to health care deviation requisites specific to risk-reduction of lymphedema	$M = 60$, Range = 35–81	14/14	Open-ended interview, thematic analysis	7
Radina, 2009	USA	Lifestyles before and after lymphedema, perceptions of personal independence, relationships with others, and personal coping	$M = 59.5$, Range = 40–78	27/27	Semi-structured interview, consensual qualitative research approach	8
Ridner, 2016	USA	The variety of issues related to lymphedema selfcare and support needs	$M = 53.8$, $SD = 6.8$	21/21	Unstructured interview, traditional content analysis	7
Sun and Armer, 2019	USA	The experience of a nurse living with lymphedema for more than two decades	65	1/1	Semi-structured interview, constant comparison	7
Tsuchiya et al., 2012	Japan	The provision of medical information influence on the problem-solving processes of survivors with lymphoedema symptoms	$M = 53.3$, Range = 39–69	10/10	Focus group discussions, inductive thematic analysis	7
Tsuchiya et al., 2015	Japan	Japanese survivors' decision-making about social disclosure of their lymphoedema symptoms in the context of social interactions	$M = 53.3$, Range = 39–69	0/10	Focus group discussions, inductive thematic analysis	7
Wanchai et al., 2012	USA	Contrast lymphoedema experiences and lymphoedema managements between breast cancer survivors from the two countries	37–87	29/29	Semi-structured interviews, thematic analysis	7
Whyte, 2010	USA	The meaning attributed by women to living with lymphedema	$M = 43.6$, Range = 31–50	10/10	In-depth semi-structured interviews, thematic analysis	9
Zhao et al., 2021	China	The experience surrounding lymphedema self-management from the perspectives of lymphedema patients	$M = 50.3$, $SD = 8.7$, Range = 34–65	13/13	Semi-structured interviews, thematic analysis	7

- no relevant data in the original literature

Fig. 1 Literature identification process



engaged in a long period of searching for a diagnosis and treatment [20]. When breast cancer survivors notice symptoms associated with lymphedema, they usually seek help from surgeons. However, some surgeons do not know about lymphedema and do not elaborate on the cause of arm problems, methods of self-management, and available therapy [27]. The lack of adequate information affect their proper diagnosis, and delay access to training in self-management skills and referral to treatment. Kozak et al. [19] reported that some surgeons suggested taking aspirin or diuretics. However, lymphedema specialists do not advocate these therapies because they are ineffective. Improper induction has made the road to treatment difficult, and survivors seek further help from books, the Internet, and self-help groups [27]. Moreover, in hospitals, particularly in an emergency, they had to be constantly vigilant to remind medical professionals that there was no blood pressure or sticks on the

arm [22]. They felt frustrated that lymphedema was not addressed, as in other chronic conditions, and there was a general lack of awareness, resources, educational investment, and insurance coverage allocated to the care of lymphedema [22].

Adherence to the treatment to control arm swelling is another difficult process. Many breast cancer survivors experience physical discomfort as their arms swell and seek intensive physical therapy again [35]. However, most are afraid of wrapping their arms and are unwilling to return to intensive physical therapy, which requires visiting a physical therapist two to four times per week for four to six weeks [35]. In the absence of financial insurance, physical therapy is considered costly to cover lymphedema therapy. Breast cancer survivors need medical and financial support to obtain lymphedema treatment and manage their lymphedema, including attention

Table 2 Findings extracted from the included studies, categories and synthesized findings

Findings	Categories	Synthesized findings
<p>A1. Lymphoedema self-management knowledge (U)</p> <p>X1. Lymphoedema knowledge (U)</p> <p>D3. Patient knowledge about lymphoedema: How and what (U)</p> <p>F1. Information gaps (U)</p> <p>H1. Insufficient information (U)</p> <p>M1. Limitations of knowing (U)</p> <p>N2. Who knows? (C)</p> <p>S3. Searching (U)</p> <p>A7. Instrumental support (C)</p> <p>L1. Seeking lymphoedema therapy (U)</p> <p>Q1. Actively sought information or treatment options (C)</p> <p>S2. Yearning for Normalcy (U)</p> <p>D2. Implications of limited physician knowledge and inadequate communication with patients (U)</p> <p>E1. The feeling of being lost (U)</p> <p>G2. Lack of resources for self-care activities (U)</p> <p>G3. Self-advocacy by default (U)</p> <p>L2. Perceived necessity of continuing therapy (U)</p> <p>T1. Keeping in mind the consequences (U)</p> <p>T2. Preventing lymphoedema from getting worse (U)</p> <p>C3. Healthcare systems and information supportive care needs (U)</p> <p>C4. Financial supportive care needs (U)</p> <p>N1. Self-preservation (U)</p> <p>A2. Self-management behaviors (U)</p> <p>K1. Using compression garments (U)</p> <p>K2. Performing physical activities (U)</p> <p>K4. Other strategies (C)</p> <p>D1. Weight struggles in patients with lymphoedema (U)</p> <p>X2. Perceptions of home monitoring (U)</p> <p>H2. Not following recommendations (U)</p> <p>B3. Passive and active coping (U)</p> <p>D4. Lymphoedema self-management challenges and coping strategies (U)</p> <p>M2. Limitations for making judgments and decisions about self-care (C)</p> <p>Q2. Learned physical strategies to manage lymphoedema symptoms (U)</p> <p>Q8. Used ineffective coping methods (U)</p> <p>Q9. Impact of their racial and socioeconomic backgrounds on coping (U)</p> <p>V1. Problem-focused coping (U)</p> <p>M3. Limitations for engagement in result-achieving courses of action (C)</p> <p>E2. Functional impairments related to lymphoedema and bandaging (U)</p> <p>E3. Being limited yet not being limited (U)</p> <p>F3. Physical challenges (U)</p> <p>O1. Making conscious decisions about new-fangled limitations (U)</p> <p>Q3. Accepted the limitations associated with lymphoedema symptoms (C)</p> <p>T3. Getting ready to live with lymphoedema (U)</p> <p>T4. Integrating the care of lymphoedema into daily life (U)</p> <p>O2. Making daily care feasible (U)</p> <p>O3. Incorporating lymphoedema care into a daily routine (U)</p>	<p><i>Category 1: Insufficient and conflicting information</i> Survivors lack knowledge about lymphoedema self-management, and even do not know lymphoedema is a complication and get conflicting information, so they often miss the best opportunity to prevent and early deal with lymphoedema</p> <p><i>Category 2: A hard road to treatment</i> Noticing lymphoedema related symptoms, most survivors turn to surgeons for help firstly, but some surgeons have inadequate knowledge about lymphoedema and give no detailed instruction, they have to seek treatment actively, take advocacy of lymphoedema and stick to treatment</p> <p><i>Category 3: Poor adherence to self-preservation</i> Survivors have to take several strategies to prevent and manage lymphoedema, but they could not exactly follow the doctor's advice</p> <p><i>Category 4: Problem-focused coping</i> Self-management is a problem-focused coping process. Survivors have to deal with lymphoedema related symptoms, limitations of arm function and the challenge of making self-management a daily routine</p>	<p><i>Synthesized findings</i> <i>Synthesized finding 1: Breast cancer survivors face challenges in the process of lymphoedema self-management</i> Breast cancer survivors lack knowledge about lymphoedema self-management and instructions on lymphoedema treatment, and could not timely prevent and deal with lymphoedema. They do poorly adhere to self-preservation as healthcare providers recommend, and have to cope with lymphoedema related symptoms, limitations of arm function and the challenge of making self-management a daily routine</p>

Table 2 (continued)

Findings	Categories	Synthesized findings
E4. Experiencing different challenges with different jobs (U) I1. Perceived responsibility of social roles within the family (U) J1. Making the time (U) J2. Struggles with putting myself first (U) U3. Crisis (U) W1. Daily tasks (U) R1. Having a visible sign: disability versus a need for help (U) R2. Having physical limitations: being handicapped versus the inconvenience (U) G1. Lack of social support (U) U1. Adjustment (U) U2. Adaptation (U) W2. Task modification (U) J3. Making a commitment to self-care (U) Q6. Openly talking and educating about lymphedema (U) P1. Stopping participation in family leisure activities that might be dangerous or difficult (U) P2. Making modifications in participation to continue their leisure time with their families (U) Q7. Maintained leisure and recreational activities (U) Q10. Reliable alliance of others besides partners (U) Q11. Concern and support from health care providers (U) C1. Physical supportive care needs (U) A8. Social support (U) B1. Social support (U) H3. social support (U) F2. Emotional responses (U) A3. Anxious (U) A4. Troublesome (U) A5. Hopelessness (U) S1. Constancy (C) S4. Abandonment (U) I2. Unsupportive reactions to BC from others (U) R3. Worrying constantly versus feeling fortunate (U) V2. Emotion-focused coping (U) B2. Downward comparison (U) Q4. Focused on the positive aspects of life (C) Q5. Used spiritual/religious methods (U) A6. Psychological support (U) C2. Psychosocial supportive care needs (U) Q1.2. Spiritual support from others (U) K3. Using faith (U)	<p><i>Category 5: Entangled in different roles</i> Women play different roles in their lives, but lymphedema self-management would restrict and demand them. Most of them make their normal social roles priority and do not want to others worry, then they have no time and no support for self-management</p> <p><i>Category 6: Rebuilding a new balance</i> To rebuild a new balance between different roles, survivors make different levels of changes in family leisure activities to perform lymphedema self-management, and the level of change depends on the level of support they get. Adequate social support would encourage them to adhere to self-management</p> <p><i>Category 7: Troubled by negative emotions</i> The uncertainty of the future, and helplessness of the treatment process and complexity of self-management bring negative emotions to survivors</p> <p><i>Category 8: Regulating emotions</i> Survivors seek internal and external resources to adjust their emotional state. They downward comparison, focus on the positive aspects of life, and use spiritual/religious methods; besides, they need emotional support from psychologists, families and friends</p>	<p><i>Synthesized finding 2: Breast cancer survivors are entangled in rebuilding a new balance between different roles</i> Lymphedema self-management conflicts with survivors' social roles, especially women's roles in family, to rebuild a new balance between different roles, survivors make changes and need support from families and peers</p> <p><i>Synthesized finding 3: Breast cancer survivors seek internal and external resources to regulate emotions</i> Survivors have various negative emotions in the process of self-management of lymphedema, and they have to adjust their emotional state by adjusting themselves and getting emotional support from others</p>

The codes before every extracted finding correspond with Table S3 (online resource 3). Each finding had an assigned level of credibility based upon ComQual approach. Unequivocal (U): relates to evidence beyond reasonable doubt which may include findings that are matter of fact, directly reported/observed and not open to challenge; Credible (C): those that are, albeit interpretations, plausible in light of data and theoretical framework, they can be logically inferred from the data, because the findings are interpretive, they can be challenged, Not Supported (NS): when 1 nor 2 apply and when most notably findings are not supported by the data

Table 3 ConQual summary of findings

Systematic review title: Experiences of breast cancer survivors with self-management of lymphedema: a qualitative systematic review		Population: breast cancer survivors		Phenomena of interest: the experiences of lymphedema self-management among breast cancer survivors		Context: all kinds of settings (e.g., home, primary care settings, hospitals, and rehabilitation centers)	
Synthesized finding	Type of research	Dependability	Credibility	ConQual score	Comments		
<i>Breast cancer survivors face challenges in the process of lymphedema self-management</i>	Qualitative	Moderate (scored 4/5 for the 5 criteria in 3 studies, 3/5 in 15 study)	Downgraded one level	Low	Credibility downgraded as the synthesized finding includes mix of 39 unequivocal and seven credible findings		
Breast cancer survivors lack knowledge about lymphedema self-management and instructions on lymphedema treatment, and could not timely prevent and deal with lymphedema. They do poorly adhere to self-preservation as healthcare providers recommend, and have to cope with lymphedema related symptoms, limitations of arm function and the challenge of making self-management a daily routine							
<i>Breast cancer survivors are entangled in rebuilding a new balance between different roles</i>	Qualitative	Moderate (scored 4/5 for the 5 criteria in 3 study, 3/5 in 10 study)	Remains unchanged	Moderate	Credibility did not downgrade as the synthesized finding includes 23 unequivocal findings		
Lymphedema self-management conflicts with survivors' social roles, especially women's roles in family, to rebuild a new balance between different roles, survivors make changes and need support from families and peers							
<i>Breast cancer survivors seek internal and external resources to regulate emotions</i>	Qualitative	Moderate (scored 5/5 for the 5 criteria in 1 study, 4/5 in 1 study and 3/5 in 10 study)	Downgraded one level	Low	Credibility downgraded as the synthesized finding includes mix of 14 unequivocal and two credible findings		
Survivors have various negative emotions in the process of self-management of lymphedema, and they have to adjust their emotional state by adjusting themselves and getting emotional support from others							

from healthcare professionals, education, lifestyle counseling, and access to healthcare sources [12].

Category 3: poor adherence to self-preservation Strategies to prevent and manage lymphedema comprise exercise (arm function exercises, walking, tai chi, and square dancing), limb elevation, wearing compression sleeves, self-manual lymph drainage (MLD), compression bandaging, and intermittent pneumatic compression [10, 23]. Despite a high level of engagement with lymphedema self-management, patients generally do not perform lymphedema self-management per recommendations [23]. Some key measures such as self-MLD and compression bandages are seldom performed or practiced at a reduced frequency [10, 29], with only a few survivors able to adhere to arm function exercises regularly. Some participants had misconceptions about exercise; they exercised only when they felt discomfort in arms and stopped when their symptoms were relieved [23]. A few survivors purchased self-management devices (intermittent pneumatic compression pump and home monitoring devices) as recommended because they are expensive and not affordable for most [26, 39]. The reasons for not following the advice varied, such as a lack of interest in achieving self-management requirements, insufficient goal orientations and values placed on self-management, and patterns of personal and family living that limit involvement in self-management activities [28].

Survivors diagnosed with lymphedema had a better understanding of lymphedema self-management than those without it. They believed that self-preservation strategies were important for controlling lymphedema and understood that lymphedema could pose serious health risks if unmanaged [29]. Although some survivors did not or could not adhere to self-preservation strategies, most knew what to do to make the best out of difficult situations [29]. Overweight survivors face more difficulty in managing lymphedema and reducing their weight simultaneously because medications for breast cancer contribute to weight gain and make it very difficult to lose weight, and excess weight makes it harder to manage the symptoms of lymphedema [19].

Category 4: problem-focused coping Survivors encounter various problems during lymphedema self-management. First, they had to adopt coping strategies to manage lymphedema symptoms, such as deliberate efforts to manage or change the situation [11]. They managed the situation by changing the environment, themselves, or both [37], “*I have to think ahead. I can’t lift very heavy things with this arm, such as moving files and other things, then I let my other arm take the punishment*” [37]. However, some survivors used ineffective coping methods that worsened the lymphedema. For example, a survivor learned to massage her arm through a video but performed it incorrectly, and the lymphedema

then moved to her hand [32]. Additionally, racial and socioeconomic backgrounds affect coping recourses [32]. One survivor described how being a White woman resulted in having more personal resources to help her cope with lymphedema, “*I think in our culture, in general, it [being White] affects everything. It doesn’t give us total access to things, but it does give us access to things other people may not have That’s just a reality There’s a lot of racism still in this old rural state. So, yes, I think definitely the fact that I have access to things, like good health insurance, you know, have good jobs, definitely makes it easier for me to cope with this*” [32].

Second, lymphedema, or the risk of developing lymphedema, has many physical function limits, such as carrying and lifting heavy objects [20]. Survivors had to accept that lymphedema would limit their activities, disturb their appearance, and require them to follow serious precautions in performing daily tasks [32]. Initially, some patients overlooked these limits and continued with previous practices, but the exacerbation of swelling and other symptoms forced them to acknowledge these limits [30]. Subsequently, they had to develop many strategies to overcome the functional limitations of lymphedema [20]; for example, to address the limitations of lifting and carrying, they used roller bags [20].

Third, adherence to lifelong lymphedema self-management was challenging. A lack of a routine for lymphedema self-management causes a high likelihood of forgetting it, irregular self-management, and unsatisfactory management effect [30]. To establish a routine, some survivors made the lymphedema self-management part of getting ready for the day and for bed. To maintain the established routine, they tried to foresee changes in their lives and plans [35].

Additionally, some problems could not be solved by survivors, and they needed medical system support, such as the cost burden of wraps and compression garments not covered by insurance [19], and a lack of sufficient antecedent and empirical knowledge to reflect [28].

Synthesized finding 2: breast cancer survivors are entangled in rebuilding a new balance between different roles

Lymphedema self-management interferes with survivors’ social roles, particularly those in the family. To rebuild a new balance between diverse roles, survivors make changes and need support from their families and peers. The following categories for entangled roles and rebuilding a new balance were identified:

Category 5: entangled in different roles Survivors have many social roles, such as housewives, mothers, and career women. However, the patient role of lymphedema self-management

restricts and interferes with social roles, particularly survivors' roles in the family. When survivors followed their doctors' or physical therapists' advice, they faced particular challenges in completing household chores [38]. They had to avoid using the affected arm to lift more than 10 pounds and reduce the number of repetitive movements [35]. Arm mobility is also compromised because of swelling, pain, or treatments. At the beginning of lymphedema treatment, the arm is initially wrapped in up to eight layers of bandages, thus making the use of the arm difficult because elbow motion is decreased and the bandages must be kept dry [38]. Although physical limitations interfere with household chores, survivors do not want others to worry; thus, they delay informing others about their condition [24].

For working survivors, lymphedema results in physical limitations at work, and they feel handicapped and inconvenient [33]. With visible signs of lymphedema, including enlarged swollen arms, puffy swollen hands, or the compression garments they wore, they experienced much distress [33]. The visible signs of lymphedema signal that survivors have disability, but most do not want people to think that there is something wrong with their arm; they try to cover the arm during work [33]. For survivors who could not cover their swelling arms, visible signs resulted in more distress [33]. A waitress shared her experience, *“My boss constantly reminded me that I would better cover my hand well so that our customers would not be scared. I understand that people might lose their appetite if they see my swollen hand, or they might think something worse. Every time I reminded myself to only use the other hand to put food on the table so that I do not give people the chance to compare [my hands], I am really stressed out, as if I had something very disgusting”* [33]. Survivors whose work demands regular lifting may receive aid without asking because of their visible symptoms although some managers are irritated by coworkers' active assistance and yell at the survivor. To preserve their employment, survivors frequently prefer to overlook their employers' verbal abuse.

Most survivors struggled with self-management activities in the context of caring for others or other responsibilities related to family life [25]. They felt obligated to sacrifice time for self-management to take social roles and considered continuing normal social roles as a priority, particularly for a survivor with child-rearing tasks [24]. Family roles as wives or mothers would take up too much time, attention, and energy, thereby leaving survivors physically and mentally exhausted to engage in self-management activities [25].

Category 6: rebuilding a new balance Breast cancer survivors made various changes to rebuild a new balance between patient and social roles, with the degree of change depending on the family's previous patterns of functioning and resources [36, 38]. Some survivors had strong family

support and could adapt well to a new balance [32]. Family members often help bandage their arms, handle household chores, and adjust work schedules or change jobs to accommodate the needs of survivors [11, 32]. However, those who lacked family support experienced crises and required help [36]. Survivors feel inspired when they receive support from peers and hear stories and recommendations [10, 11]. However, they sometimes feel a lack of social support and receive negative verbal and nonverbal reactions from others, such as insensitive comments and strangers staring at their arms [22, 24]. People around them usually seem oblivious to the chronic nature of lymphedema [22], and, with insufficient support, survivors may selectively disclose their illness [24].

To adapt to the patient role, survivors who do not want to or do not perceive the need to stop participating in certain family leisure activities because of lymphedema change or rethink their participation (i.e., getting different equipment and planning how they will participate more carefully). They limit their participation in outdoor activities and take precautions to protect themselves, such as avoiding sunburns and insect bites that may lead to infection [38]. Moreover, they stop participating in certain activities that may worsen the lymphedema [31].

Synthesized finding 3: breast cancer survivors seek internal and external resources to regulate emotions

Survivors experience negative emotions during lymphedema self-management, and they must manage their emotional state by adjusting themselves and getting support from others. Two categories were identified: negative emotions and emotion regulation.

Category 7: troubled by negative emotions Breast cancer survivors experience complex emotions during lymphedema self-management [21]. Patients felt troubled when they began treatment and management of lymphedema because it is a complex and time-consuming process [10]. They felt anxious because lymphedema was recently recognized as an incurable condition and lacked symptom improvement and progression despite self-management, and hopeless because self-management did not work as they expected [10]. It is frustrating, tiring, and annoying for breast cancer survivors to regularly deal with lymphatic limbs [34]; they many become depressed because they have to live with lymphedema for the rest of their lives [10]. Additionally, they felt marginalized that lymphedema was not addressed as in other chronic conditions [10], particularly for survivors whose jobs required lifting and constant use of the arms and hands and those whose supervisors or employers were neither understanding nor supportive [33]. One survivor described her experience of being scared that she would

lose her job at any time, “Mr. XX [my supervisor] did not understand my situation as a breast cancer survivor with lymphedema. He was upset when I tried to explain to him the difficulties I had at work, such as holding the sample tube for vibration and pushing or pulling heavy objects. When he saw my swollen hand and arm getting worse, he yelled and shouted at me, saying, ‘You should just stay home.’ I am scared that I will lose my job any time” [33].

Category 8: emotion regulation To deal with negative emotions, survivors compared their experiences with patients whose condition was less understood, which helped them feel better than others and generated a sense of gratitude and comfort [11]. Another way is to adjust their values to present-day reality, for example, accepting changes in physical appearance, “I have changed my values. I don’t care about things like that (the arm’s appearance) today. The main thing is that I am healthy. So, that does matter” [37]. Some patients use religious methods (e.g., prayers, meditation, or believing in a higher power) to cope with lymphedema [32], “I know that God just chose to answer my prayers in His good time. That’s how I feel and now I ask more on behalf of other people and for me to cope, not to change things” [32].

In addition, survivors seek psychologists to help them manage their emotions because they trust experts more and want encouragement, comfort, and a giving approach to regulate negative emotions. They also emphasize that receiving emotional support would empower them to cope with self-management [10], and they need someone to rely on [12]. Receiving sincere support, understanding, and prayers empowered them to fight lymphedema [12, 32]. One survivor said this about prayer, “My boss asked me if I wanted him to put me on his prayer list at church. And I said ‘yes.’ And a couple of days later, I could tell. I could feel the difference... and it helped me cope” [32].

Discussion

Our synthesis provides insight into how survivors take action to manage lymphedema. Breast cancer survivors face many challenges in lymphedema self-management. They lack knowledge about lymphedema self-management and instructions on lymphedema treatment, and it is challenging to adhere to self-preservation and cope with various problems. Additionally, they have to rebuild a balance between different roles and regulate negative emotions. It is difficult for survivors to adhere to lifelong lymphedema self-management; they need information and instrumental and emotional support, particularly from healthcare providers and families.

Lifelong lymphedema self-management is challenging for survivors, and they need information and instrumental support

The American Physical Therapy Association (APTA) highlighted the fact that interventions for cancer-related lymphedema should begin at the diagnosis of breast cancer and continue through cancer treatment and survivorship [6]. Therefore, effective early and continuous self-management education is important. However, most survivors lack sufficient knowledge, and always rely on surgeons. However, education is not the main duty of surgeons and they tend to leave it to lymphedema therapists [19]. Hanna et al. reported that majority of survivors received information from their surgeons and medical oncologists, while only a few were informed by physical/occupational therapists. However, survivors thought useful information mostly comes from physical/occupational therapists, while that from surgeons and medical oncologists is not useful [40]. There was a marked underuse of rehabilitation services, which might have led to low awareness of rehabilitation by both patients and referring clinicians, restricted access to services, and suboptimal adherence [41]. Thus, access to physical therapy for patients with lymphedema should be made more available, and physical therapists should advocate their role in lymphedema education.

Recently, lymphedema self-management education is no longer limited to printed materials; multimedia is gradually being applied [42, 43], and survivors can acquire knowledge on websites and applications. However, Omidi et al. [44] found that group-based education is more beneficial than social-network-based education. Thus, the cost-effectiveness of the education model needs to be explored further.

Self-management education alone is insufficient for survivors for lifelong lymphedema self-management [45]. According to the synthesized findings, survivors generally did not perform the procedure according to recommendations [10, 29]. Brown et al. established that only 31% of the survivors had $\geq 75\%$ adherence to all lymphedema self-management behaviors over 12 months [9], and greater adherence was associated with stronger beliefs about lymphedema controllability, self-efficacy, perceived consequences, and perceived self-regulatory ability [46]. To improve patients’ adherence to lymphedema self-management, promoting survivors’ positive beliefs regarding the controllability of lymphedema should be combined with self-management education [46]. Survivors need instrumental support to adhere to self-management, which refers to tangible support, such as helping survivors perform lymph drainage and wear compression sleeves [12]. Instrumental support can effectively help them internalize knowledge and adjust their daily lives [15].

Survivors are entangled in rebuilding a new balance between different roles and need family support

When self-managing patients assume the tasks of role management, they are deemed to maintain, change, or create new meaningful behaviors or life roles to manage the disease and its associated effects [7]. As survivors usually perform self-management behaviors in a family situation [47], family members can strongly support them [48], and survivors benefit from solid partnerships with family members [48]. Therefore, it is better to encourage family members to participate in lymphedema self-management programs for survivors. However, lymphedema self-management programs are often aimed at educating and instructing the survivors and do not emphasize the participation of family members [42, 49].

Emotion regulation is important in lymphedema self-management, and emotional support should be valued

Emotional management is important, and the way individuals manage their emotions can influence how they perform their roles and medical management [7]. Breast cancer survivors may develop various negative emotions in lymphedema self-management, such as fear, dread, overwhelming trouble, hopelessness, and worry. Fu et al. [50] reported that lymphedema caused survivors to have negative self-identity, emotional disturbance, and psychological distress. Psychological factors lead to low adherence to lymphedema self-management [8], which is why survivors' emotions should be considered. Breast cancer survivors require emotional support to cope with self-management. However, a systematic review of self-management support strategies revealed that only 43.9% of the studies in primary healthcare practice involved strategies for psychological coping with conditions [51]. Several emotional interventions significantly regulate the emotions of breast cancer patients, such as muscle relaxation training [52] and yoga [53], keeping a diary, or participating in meaningful charity activities [48]. In the future, these effective emotional interventions should be incorporated into lymphedema self-management programs.

Recommendations for practice

The practice recommendations were based on the categories and synthesized findings of this study, and the recommendations were graded according to the JBI grades [16]. We compiled breast cancer survivors' experiences in lymphedema self-management, thus demonstrating that lifelong lymphedema self-management is complicated and that survivors need various forms of support.

- Healthcare providers should provide patients with breast cancer with timely lymphedema self-management education, and physical therapists should advocate their role in lymphedema education, as they can provide the most useful information to survivors. The cost-effectiveness of the education model needs to be explored further (grade B).
- Self-management education alone is insufficient for survivors to adhere to lifelong lymphedema self-management, and instrumental and emotional support should be provided to help survivors solve tangible and emotional problems (grade B).
- Access to lymphedema treatment and related resources should be more available, and financial support should cover the treatment of lymphedema and associated medical expenses (grade B).
- Family members should participate in survivors' lymphedema self-management, help survivors prioritize self-management, and rebuild a balance between different roles (grade A).

Strengths and limitations

This review synthesizes studies exploring the experience of breast cancer survivors in lymphedema self-management. Owing to English language limitations, we may have missed studies published in other languages. Our synthesis excluded participants affected by primary and secondary lymphedema caused by other diseases and studies wherein data from participants with lymphedema were not separately reported, which might have led to a loss of useful information. As most studies did not involve and clarify the definition of self-management, the included findings were screened and judged by the authors according to their operational definition of self-management, which would have led to some findings being missed due to authors' partial understanding. Additionally, we did not include grey literature and might have missed research that had not been formally published.

Conclusion

Lymphedema self-management is a lifetime commitment and a challenge for breast cancer survivors. Survivors find it difficult to adhere to self-management and cope with their problems, and they require timely and continuous effective self-management education. Moreover, they need instrumental and emotional support from others, particularly from healthcare providers and family members.

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Declarations

Ethical approval This article does not contain any studies with human participants performed by any of the authors.

Conflict of interest The authors declare no competing interests.

Registration The study protocol was registered in PROSPERO (<https://www.crd.york.ac.uk/prospero/>) in September, 29, 2021 (CRD42021275902).

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