



Patient education for breast cancer–related lymphedema: a systematic review

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Abstract

Purpose The aim was to identify the impact of the (a) components of breast cancer–related lymphedema (BCRL) educational content, (b) modes of education, and (c) timing of education on arm volume, quality of life, function, complications associated with BCRL, adherence to interventions, and knowledge acquisition in individuals diagnosed with breast cancer (BC).

Methods This review followed the Preferred Reported Items for Systematic Review and Meta-analysis (PRISMA) guidelines (PROSPERO CRD42021253084). Databases searched included PubMed, CINAHL, Web of Science, Google Scholar, and Scopus from January 2010 to December 2021. Study quality and bias were assessed using the American Physical Therapy Association’s Critical Appraisal Tool for Experimental Intervention Studies.

Results Forty-five studies were eligible, and 15 met the inclusion criteria (4 acceptable and 11 low quality). This review was unable to determine the optimal content, mode, and timing for BCRL education across survivorship. Content included a brief overview of BCRL, early signs and symptoms, risk reduction practices, and a point of contact. Delivery was multi-modal, and knowledge acquisition was rarely assessed. Education was provided pre/post operatively and after BCRL developed.

Conclusions Individualized BCRL education via a multi-modal approach, repeated at multiple time points, and assessment of survivors’ knowledge acquisition is recommended. Consideration of the survivors’ phase of treatment, content volume, and time required to complete the program is advised when developing the educational intervention.

Implications for Cancer Survivors Survivors of BC may need to advocate for BCRL education based on their individual risk and needs, request a point of contact for questions/follow up, and express their preferred style of learning.

Keywords Breast cancer · Lymphedema · Patient education · Survivorship · Systematic review

Introduction

Breast cancer–related lymphedema (BCRL) impacts approximately 19% of survivors of breast cancer (BC), most commonly within the first 2 years after treatment [1, 2]. Individuals who develop lymphedema often demonstrate upper quadrant functional impairments, decreased participation in social activities, higher medical costs, and a lower quality of life [1–7]. Additionally, the impact of BCRL may result in a myriad of psychosocial responses, such as high levels of anxiety, depression, uncertainty, and lower self-esteem that occur throughout survivorship [8].

Due to the negative impact of BCRL, an educational intervention has the potential to increase the individual’s awareness of risk factors, early signs and symptoms, and treatment options that could lead to earlier detection and better control of BCRL [9–11]. Once BCRL does develop, education is also needed on skin hygiene, prevention of

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infection, and self-care practices. Healthcare professionals and those diagnosed with BC agree patient education is a key component of both prevention and treatment of BCRL; however, individuals diagnosed with BC report having inadequate knowledge about lymphedema and its sequela across the trajectory of survivorship [12–14]. A contributing factor may be the lack of guidance for healthcare professionals when developing an educational intervention throughout survivorship [15].

The goal of this systematic review was to evaluate the available evidence on BCRL education for individuals at risk and those who have developed the condition and to identify gaps in the literature to direct future research. The primary aim of this systematic review is to identify the impact of the different (a) components of BCRL educational content, (b) modes of education, and (c) timing of educational intervention across the trajectory of BC care. The secondary aim is to examine the effect of patient education on arm volume, quality of life, function, complications associated with BCRL, adherence to interventions, and knowledge acquisition in individuals diagnosed with BC.

Methodology

Study design and search strategy

This systematic review (PROSPERO registration number: CRD42021253084) was conducted following the Preferred Reported Items for Systematic Review and Meta-analysis (PRISMA) guidelines. A literature search with the assistance of an academic librarian from the University of Southern California using the timeframe from January 1, 2011 to December 31, 2021 was conducted. Electronic databases searched included PubMed, CINAHL, Web of Science, Google Scholar, and Scopus. The final search terms were Lymphedema, Elephantiasis, and truncated text words lymphedema*, lymphoedema*, elephantiasis, patient education, risk reduction practices, precautions, prospective surveillance, and BC. Two independent reviewers screened the title and abstracts and applied the inclusion and exclusion criteria. Inclusion criteria included the following: quantitative study design; adults ≥ 18 years old; BC, at risk or with secondary lymphedema; education as an intervention; one measure related to quality of life, function, volume measures, adherence, complications, knowledge assessment, and English language studies only. Exclusion criteria included the following: case reports, case series, qualitative study design, literature reviews, editorial, letter, presentations, dissertations, and comments; studies including the terms filariasis, parasites, congenital, hereditary; adolescents < 18 years old,

primary lymphedema; other cancer-related lymphedema; other causes of secondary lymphedema; lower extremity lymphedema; pelvic or genital lymphedema, and animal studies (Fig. 1).

Quality appraisal

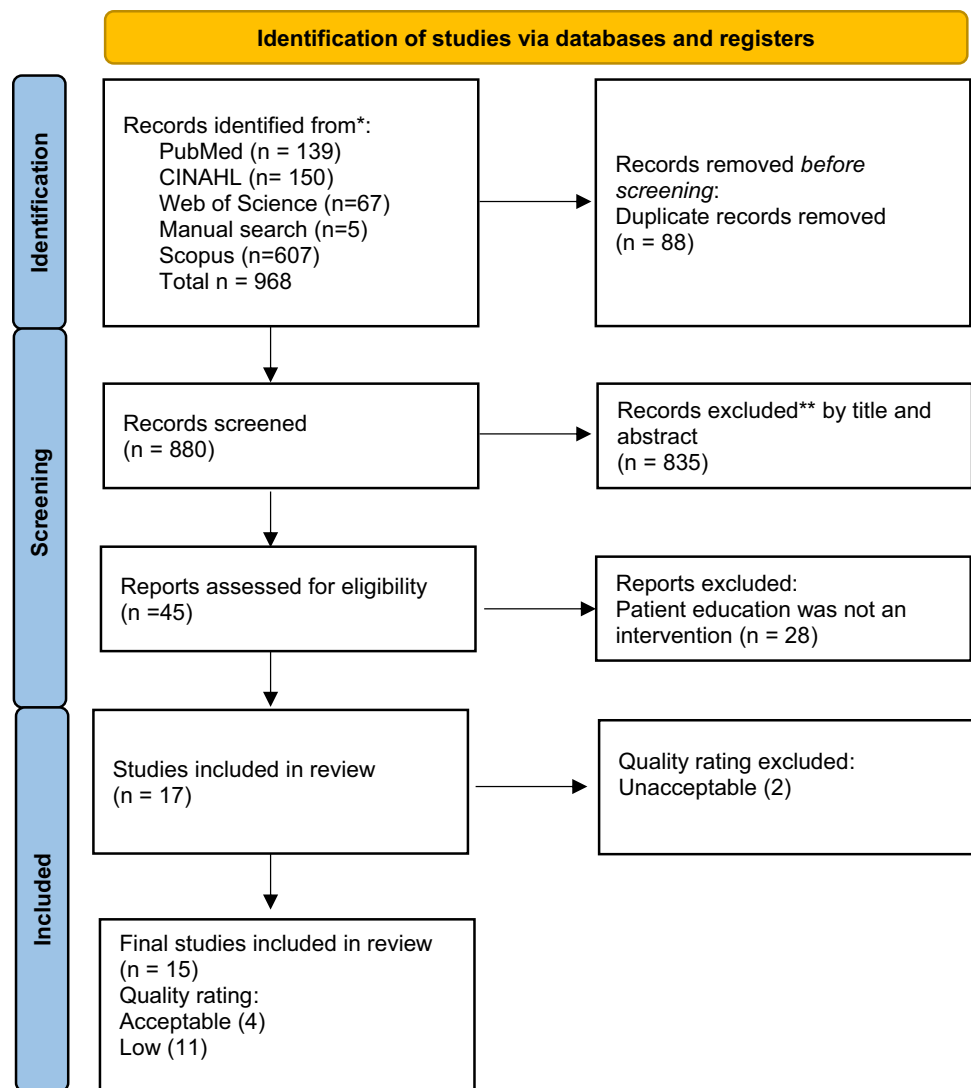
Study quality was assessed using the American Physical Therapy Association's (APTA) Critical Appraisal Tool for Experimental Intervention Studies (CAT-EI). [16]. The CAT-EI assesses bias risk in clinical research and was used to assign a quality rating. Two reviewers independently appraised 3 studies to establish a quality rating agreement. The same reviewers then independently appraised the remaining studies and if quality-rating consensus did not agree, a third reviewer was used. The quality level rating was based on the APTA Clinical Practice Guideline recommendations [16]. The reviewers followed the recommendations for the APTA CAT-EI manual for determining quality ratings. The review group agreed upon the following essential scoring criteria that need to be met with a "YES" answer in order to be assigned a quality rating [16]. The following questions were utilized from the CAT-EI:

1. Was the patient population appropriate for the study question?
2. Was the study a randomized control trial?
3. Did the sample size meet power requirements for the outcome of interest?
4. Was the tester and/or data collector blinded to the treatment group of interest?
5. For each outcome of interest, was a measure chosen that had established validity?
6. For each outcome of interest, was a measure chosen that had established reliability?
7. Were the appropriate statistical analysis chosen (e.g., subjects analyzed in the groups to which they were assigned)?
8. Was their adequate follow-up (at least 1 month for intervention studies)?

If the study met all 8 of the essential scoring items by 2 independent reviewers, the study received a "high-quality rating." For an acceptable quality rating, the study needs to meet 6 of the 8 criteria. Likewise, a low-quality rating score was assigned if the study met between 2 and 5 of the criteria. Finally, an unacceptable quality rating was assigned to those studies scoring 0–1.

The evidence for BCRL patient education as an intervention was appraised and synthesized. The extracted data included (a) the components of BCRL educational content,

Fig. 1 PRISMA flow chart illustrating the inclusion and quality rating of studies reviewed



(b) modes of education, and (c) timing of educational intervention (Table 1).

Results

The search identified 968 studies and 45 underwent full-text review. Seventeen studies published between January 2011 and December 2021 met the study inclusion criteria and were included in the review. The review did not yield any high-quality studies, and 2 were deemed unacceptable. As a result, 15 studies of acceptable and low quality were included (4 acceptable and 11 low quality). Five of the studies were conducted in the USA, 2 studies each were conducted in China and Turkey, and 1 study from each of the following countries: Australia, Canada, Italy, Iran, Japan, and Taiwan. There were 9 randomized

controlled trials, 1 retrospective, and 5 prospective pre/post study designs.

Study characteristics

Demographic characteristics

Participants across all studies (combined $N=2230$) were women diagnosed with BC with or without lymphedema that received education. Participant demographics varied and included at least some or all of the following characteristics: mean age of 53.9 years (range 47.43–61.0), mean body mass index of 25.75 (range 23.91–35.0), stages of BC ranged from I to III, axillary lymph node dissection, sentinel node biopsy, radiation therapy, and chemotherapy [9, 17–30]. Ten of the studies examined education for those at risk of developing BCRL, and 5 studies included women previously diagnosed

Table 1 Risk of Bias according to the APTA CAT-EI Tool

Author, year, quality level	I	C	EC	Recruitment minimize bias	A priori power analysis	Randomly assigned to intervention	Treatment group concealed	CG	Subjects blinded to treatment group	Intervention reproducible	Adherence described	Adverse effects	Conflict of interest
Bozdemir 2021, II Acceptable	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y
Omid, 2020, II Acceptable	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	N	Y
Bland, 2019, II Acceptable	Y	Y	Y	Y	N	Y	N	Y	N	Y	N	N	Y
Simoncini 2017, II Acceptable	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y
Cansiz, 2022, III Low	Y	Y	Y	NA	Y	NA	NA	N	NA	Y	Y	N	Y
Paskett, 2021, III Low	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	N	Y
Liu, 2021, III Low	Y	Y	Y	N	N	N	N	N	N	Y	Y	N	Y
Naughton 2021, III Low	Y	Y	Y	Y	N	Y	N	Y	N	Y	Y	N	Y
Koelmeyer, 2020, III Low	Y	Y	Y	Y	N	N	N	N	N	Y	Y	N	Y
Ridner, 2020, III Low	Y	Y	Y	Y	N	Y	N	Y	N	Y	Y	N	Y
Zhang, 2020, III Low	Y	Y	Y	N	N	Y	N	Y	N	N	N	N	Y
Arinaga, 2016, III Low	Y	Y	Y	N	Y	N	N	N	N	Y	Y	Y	ND
Lu, 2015, III Low	Y	Y	Y	N	N	N	N	Y	N	Y	N	N	Y

Table 1 (continued)

Author, year, quality level	IC	EC	Recruitment minimize bias	A priori power analysis	Randomly assigned to intervention	Treatment group concealed	CG	Subjects blinded to treatment group	Intervention reproducible	Adherence described	Adverse effects	Conflict of interest
Singh, 2013, III Low	Y	Y	N	N	N	N	Y	Y	Y	N	N	Y
Cho, 2012, III Low	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	Y

IC inclusion criteria, EC exclusion criteria, Y yes present, N no absent, CG Control Group, ND not declared, NA not applicable

with BCRL, stage I, II, or III. These participants presented with a wide range of mean duration of lymphedema from 6.86 months (SD 3.7) [20, 29] to > 5 years [27, 30].

BCRL education

Timing of BCRL education occurred at multiple time points across the trajectory of BC care. The pre-operative phase of BC care included one-on-one in person education with a healthcare professional [17, 21–24]. During this encounter, printed educational materials regarding post-operative BC care and BCRL risk reduction and protective measures were provided. Timing allotted for this educational session varied and either lasted up to 40 min [24] or was not reported [17, 23]. Follow up educational content was repeated either post-operatively [24] or at 6 months [17, 23]. In the studies reviewed, although education was a primary aim, only one investigated knowledge assessment and its acquisition [24]. Additionally, outcome measures varied and focused on function, quality of life, arm volume, BCRL incidence rates, and adherence to self-care. The education provided also varied in timing, mode, content, and frequency across the trajectory of care. The details are provided in Table 2.

The post-operative phase of BC care utilized 3 different modes of education, which included one-on-one [19], small groups (3–4 participants) [18, 20], or social media (WeChat) [26]. During the one-on-one session, printed material with an accompanying visual presentation was conducted. BCRL content included risk reduction practices, shoulder range of motion, self-management, and physical activity. The group sessions offered similar content with the additional inclusion of BCRL behavioral strategies [20]. Education delivered via social media focused on participants' discussion of self-identified problems followed by group-guided solutions. A healthcare professional then summarized the solutions identified by the participants [26]. Only one study provided follow up education via WhatsApp at 1 and 3 months post-operatively [19]. Unfortunately, the studies did not delineate between the confounding variables, the outcome of the education intervention, and the development of BCRL.

For individuals who developed BCRL, education was provided in a variety of modes including one-on-one sessions, [27, 28, 30], small group (3–5 participants) [20], social media (Telemessenger) [20], and web-based video presentation [29]. The education used printed materials, visual aids, group discussion, demonstration, and feedback as learning modes [20, 27–30]. The BCRL education emphasized self-care and self-management, therapeutic exercises, self-manual lymph drainage, and utilization of a compression garment [20, 27–30]. Timing of each session ranged from 30 to 90 min over 4 to 5 sessions. The 12 web-based videos took 20–45 min to review [29]. Ridner et al. found the shorter the educational time expectation, the higher the completion of the program

Table 2 Summary of breast cancer-related lymphedema educational content, mode, and timing

Author, year, (quality rating) timing study design	Characteristics of participant in the intervention group	Mode of BCRL education delivery for intervention group	Educational content for intervention group	Additional rehabilitation treatments for the intervention group (PT or lymphedema specialist)	Educational content for control group	Mode of delivery for control group	Knowledge/learning assessment
Bland, 2019, (A) Pre-operative RCT	<i>n</i> = 64 BC stage: 0, I, II, III, IV Surgery: Mastectomy+axillary surgery Lumpectomy+axillary surgery Lumpectomy Mean age: 52.64 years	One on one Booklet, Lecture, discussion, Patient education manual Training repeated at 1 time point (6 months)	Education on protective measures: injury, infection, overheating, overexertion, constriction	None reported	Standard pre-op BC surgical counseling: discussion with surgeon, risk, and complications of surgery, "mentioned BCRL with some protective care"	One on one discussion, Booklet	No knowledge assessment following education reported
Bozdemir, 2021, (A) Post-operative RCT	<i>n</i> = 29 BC stage: II and III Surgery: MRM BC protection surgery+ALND or BC protection surgery+SLND Overall mean age: 48.9±9 years	Post-op with a nurse Telephone consultancy Training booklet with link to WhatsApp Education repeated at 2 time points	Definition of lymphedema, signs and symptoms, risk factors, prevention, exercises, and self-lymph massage	None reported	Standard nursing care questions answered as needed	Not reported	No knowledge assessment following education reported
Simoncini, 2017, (A) Post-operative RCT	<i>N</i> = 84 BC tumor size: 0, 1, 2, 3, X Surgery: Total mastectomy+ALND Nipple sparing mastectomy+ALND Quadrantectomy+ALND ALND Mean age: 50.6 (10.9) years	Post-op group ED guided by PT Group rehab supported by visual information—1 session 3–4 people discussion supported by images. Interactive methods and cognitive behavioral strategies	Lymphatic system; definition of lymphedema, signs and symptoms, lymphedema, and axillary web syndrome; when and how to do exercises, joint range, and muscle Strengthening, QoL advice	GRV: 20.2% needed additional information and 39.2% needed physiotherapy for axillary web syndrome, edema or difficulty with shoulder ROM	Lymphatic system; definition of lymphedema, lymphangitis, lymphedema, and axillary web syndrome; when and how to do exercises, joint range, and muscle Strengthening, QoL advice	UR: one on one education session with PT X 1 session 23.2% needed additional information and 46.3% needed physiotherapy	No knowledge assessment following education reported
Omidi, 2020, (A) Diagnosed with BCRL	Group <i>n</i> = 32 Social Network <i>n</i> = 34 BC stage: I, II, III, IV Surgery: MRM BCS BCRL stage: I, II, III diagnosis established by a MD Age: Group: 52.47 (10.62) Social network 50.44 (8.81) BMI: Group 28.04 (5.07) Social network 28.41 (5.10) Duration of LE (months): Group 6.22 (3.86) Social network 7.50 (3.510)	Group-based ED ED material presented in 5 sessions 60 to 90 min each 2×weekly with 4 sessions of LE self-management and one session stress-management Social network ED Telegram messenger where ED upload 2×week for 3 weeks. 20 audio and photo messages provided. Confirmation of information received	ED same for both groups and included: lymphedema self-management education and stress management strategies; problem solving and decision-making; using resources, applying personalized cares, cooperating with treatment team, and sharing skills with caregivers	All participants received routine BCRL treatment by a lymphedema specialist; 20 sessions of CDT, brochure on care/prevention of BCRL and CD for rehabilitation exercises	Included: lymphedema self-management education and stress management strategies; problem solving and decision-making, using resources, applying personalized cares, cooperating with treatment team, and sharing skills with caregivers	CD of educational content at end of study	No knowledge assessment following education reported

Table 2 (continued)

Author, year, (quality rating) timing study design	Characteristics of participant in the intervention group	Mode of BCRL education delivery for intervention group	Educational content for intervention group	Additional rehabilitation treatments for the intervention group (PT or lymphedema specialist)	Educational content for control group	Mode of delivery for control group	Knowledge/learning assessment
Singh, 2013, (L) Pre-operative Prospective quasi-experimental	n = 41 BC stage: DCIS, I, II, III, unknown Surgery: MRM BCS Age: 55.1 (14.8) years BMI: kg/m ² 27.1 (5.4)	Same as control group One on one with PT and printed educational materials Monitoring visits at 1 and 6 months	Standard post op care: post op exercise for mobility including AROM and AAROM; activity modification scar massage and prevention of BCRL General information (definition of lymphedema, time course of development, early signs, and symptoms), risk reduction behaviors; modifiable and non-modifiable risk factors Same as control group + further BCRL self-management strategies: lymphedema management, compression bandaging/garment, progression of shoulder exercises and scar massage as needed	Individualized PT as needed	Standard post op care: post op exercise for mobility including AROM and AAROM; activity modification scar massage and prevention of BCRL General information (definition of lymphedema, time course of development, early signs, and symptoms), risk reduction behaviors; modifiable and non-modifiable risk factors	One on one with PT and printed educational materials	No knowledge assessment following education reported
Cho, 2012, (L) Pre-operative Post-operative RCT	Papilla gown n = 30 Papilla gown + ED n = 28 Ed = 58 BC stage: II and III with ALND Surgery: total mastectomy or MRM with drain Overall mean age: 55.2 (12.6)	Pre-op one on one ED sessions with nurse for 40 min Post-op ED session with nursing reinforcing lymphedema prevention No further training	Pre-op: reach to recovery exercises; pictorial handbook of post-surgical BC care and BCRL management Post-op: Understanding and Prevention of BCRL, arm swelling and shoulder immobility	None reported	Standard care: standard hospital gown + post-op surgical instruction; but not described	One on one by nurse or surgeon	Investigator-designed BC knowledge questionnaire Significant higher knowledge scores for those who had education 0.36 (95% CI 0.30–0.40) compared to no education 0.11 (95% CI 0.07–0.15) p = 0.0001
Paskett, 2021, (L) Pre-operative RCT	Lymphedema education and prevention n = 68 Surgery: Partial mastectomy/lumpectomy/biopsy Mastectomy SLND/ALND Age: 58 (27–88)	One on one ED with lymphedema expert Follow up at 12 and 18 months post-surgery Adherence reminder telephone call at 9 and 15 months	ACS guidelines Lymphedema etiology, signs and symptoms, and preventative self-care practices Garment use during exercise (study or personal), air travel and/or vigorous activity. Juzo class I 20–30 mmHg	PT assessment and instruction on individualized 15 min exercise regime involving breathing, stretching, strengthening (2# hand weight) and personalized ROM exercises. Home video	One on one Ed with lymphedema expert Address verification telephone call at 9 and 15 months	ACS guidelines for lymphedema care/prevention Lymphedema etiology, signs and symptoms, treatments, and preventative self-care practices	No knowledge assessment following education reported
Naughton, 2020, (L) Pre-operative RCT, secondary analysis of Paskett, 2021	Lymphedema education and prevention n = 68 Surgery: Partial mastectomy/lumpectomy/biopsy Mastectomy SLND/ALND Age: 58 (27–88)	One on one ED with lymphedema expert Follow up at 12 and 18 months post-surgery Adherence reminder telephone call at 9 and 15 months	ACS guidelines Lymphedema etiology, signs and symptoms, and preventative self-care practices Garment use during exercise (study or personal), air travel and/or vigorous activity. Juzo class I 20–30 mmHg	PT assessment and instruction on individualized 15 min exercise regime involving breathing, stretching, strengthening (2# hand weight) and personalized ROM exercises. Home video	One on one Ed with lymphedema expert Address verification telephone call at 9 and 15 months	ACS guidelines for lymphedema care/prevention lymphedema etiology, signs and preventative self-care practices	No knowledge assessment following education reported

Table 2 (continued)

Author, year, (quality rating) timing study design	Characteristics of participant in the intervention group	Mode of BCRL education delivery for intervention group	Educational content for intervention group	Additional rehabilitation treatments for the intervention group (PT or lymphedema specialist)	Educational content for control group	Mode of delivery for control group	Knowledge/learning assessment
Lu, 2015, (L) Post-operative Cohort study	ED $n = 672$ ED + PT $n = 130$ BC stage: I, II, III Surgery: BCS Simple mastectomy MRM ALND Age: ED 52.67 ± 11.01 ED + PT 51.88 ± 10.08 BMI: Ed 24.24 ± 3.75 ED + PT 23.91 ± 3.65	ED with PT, ED alone published guidelines from NLN; patient-centered ED program if requested with specialized PT printed material One visit, no further training	Lymphatic system, signs of BCRL, prevention strategies, postop ex, modifying ex, scar massage, maintain healthy body weight, avoid trauma or infection, venipuncture of limb	PT provided Breathing ex, post-surgical positioning, scar massage, soft tissue stretching, shoulder mobilizations and exercises	No education and no physical therapy	N/A	No knowledge assessment following education reported
Zhang, 2020, (L) Post-operative RCT	$n = 43$ BC stage: I and II BCRL stage: I, II and III Age: 47.43 ± 6.81 BMI: 24.8	Problem-based learning with nurse facilitators. One on one and groups sessions (3–5 women per group); use of books, internet, health ED, posters, brochures; WeChat group	Patient self-care, proper ex, use of compression sleeve and body massage; other BC issues as proposed by patients during group discussions	None reported	Basic health guidance on post-op diet, early functional rehabilitation, chemotherapy, radiation, PICC and PORT catheter maintenance	30 min lecture 2 x week prior to d/c; s/p discharge health ED content via WeChat weekly for self-management	No knowledge assessment following education reported
Koelmeyer, 2020, (L) Post-operative Prospective single group intervention	$n = 20$ Node positive invasive BC Surgery: mastectomy ALND or SLND High risk for BCRL Age: 54 (12) BMI: 26 (5)	Package provided Twice per week for 30 min during hospital admission. Once per week for 30 min following discharge Unknown for weeks duration	Prospective surveillance model of care that consisted of BIS monitoring, education, and support to promote self-management and physical activity Education—risk minimization and provision of the Australian Cancer Council Understanding Lymphoedema fact sheet. Self-management strategies included skin care, exercise, self-lymphatic drainage massage, compression, and use of pneumatic compression 6 months follow up	If participants had increased LDex score about normal, or observable signs of BCRL, referred to “Lymphoedema therapist” for standard clinical care (not defined)	NA	NA	No knowledge assessment following education reported

Table 2 (continued)

Author, year, (quality rating) timing study design	Characteristics of participant in the intervention group	Mode of BCRL education delivery for intervention group	Educational content for intervention group	Additional rehabilitation treatments for the intervention group (PT or lymphedema specialist)	Educational content for control group	Mode of delivery for control group	Knowledge/learning assessment
Ridner, 2020, (L) Diagnosed with BCRL RCT	n = 47 Surgery: BCS Mastectomy BCRL stage: 2 diagnosis as per International society of lymphedema Age: 59.8 (8.6)	Web-based multimedia with Videos 12 videos each 20–45 min; long narrative, reflective questions and interviews from patients sharing stories of living with BCRL. To be completed within 1 month	BCRL self-care: Physiology of lymphatic system, self-care tasks, goal setting, rewards, diet and exercises, methods of dealing with negative emotions and stress, body images changes, uncertainty and enhancing emotional and instrumental social support. Looking at life from a different perspective and a new identity	N/A	BCRL risk reduction, early warning signs, Rx advice, emotions and LE To be completed within 1 month	Educational Pamphlet	No knowledge assessment following education reported
Arinaga 2016 (L) Diagnosed with BCRL Prospective longitudinal single group pre-post intervention	n = 23 Surgery: BCS Mastectomy ALND SLND BCRL stage: I+II per common terminology Months since onset of BCRL: 17.00 (1 to 132) criteria for adverse events Age: median 61 (29–71) years BMI: 23.1 (19.3–31.1)	One meeting to teach Self-care program to be completed for 10 min daily Phone call follow up at 1 week, 2, 4, 5 months	Self-care including basic self-care education not explained, Japanese radio calisthenics, skin moisturizing with grapefruit oil and sweet almond massage oil, self-lymphatic drainage	N/A	N/A	N/A	No knowledge assessment following education reported
Cansiz 2022 (L) Diagnosed with BCRL Prospective Quazi-experimental	n = 44 BC stage: I, II+III Surgery: MRM 72.7% BCRL stage: slight, moderate, and Marked acciffication Stillwell classification Age: 52.6 ± 8.3 BMI: 20–25 31.8% 25–30 45.5% 30–35 22.7%	Face to face education program with a nurse Oral presentation with visual content supported by a PowerPoint erPoint Question and answers Booklet 40 min 12-month follow up by phone	Self-management lymphedema Definition of BCRL Its causes, skin care, conditions to be considered, compression therapy, self-manual lymphatic drainage, movements to avoid, benefits and aims and types of exercise Exercise and self-manual lymphatic drainage 3 days per week 2 times per day for 12 months To wear compression while exercising and during day	N/A	N/A	N/A	No knowledge assessment following education reported

Table 2 (continued)

Author, year, (quality rating) timing study design	Characteristics of participant in the intervention group	Mode of BCRL education delivery for intervention group	Educational content for intervention group	Additional rehabilitation treatments for the intervention group (PT or lymphedema specialist)	Educational content for control group	Mode of delivery for control group	Knowledge/learning assessment
Liu, 2021 (L) Diagnosed with BCRL Longitudinal quasi-experimental	$n = 41$ BC stage: I, II + III Surgery: BCS Partial mastectomy Total mastectomy MRM BCRL stage: Subclinical or mild stage due to a limb circumference difference of 1–3 cm Age: 58.0 ± 12.48 BMI: 25.17 ± 3.25	Face to face individual education session Handbook demonstration and feedback of exercises 30 min Follow up 4 face to face review sessions at 1, 3, 6, and 12 months 15 telephone contacts— one per week first month then 1 per month for 11 months	Optimal lymph flow program daily self-management strategies including basic knowledge about BCRL, exercises to promote lymph flow and drainage, arm precautions to improve limb functional status, instructions to optimize BMI	N/A	N/A	N/A	No knowledge assessment following education reported

A acceptable quality, L low quality, QoL quality of life, BC breast cancer, BCRL breast cancer-related lymphedema, BMI body mass index, PT physical therapist, ED education, CDT complete decongestive therapy, Ex exercises, NLN National Lymphedema Network, N/A not applicable, BCS breast conserving surgery, MRM modified radical mastectomy, ALND axillary lymph node dissection, SLND sentinel lymph node dissection, LN lymph node, LE lymphedema, RCT randomized controlled trial, SD standard deviation, ISL International Society of Lymphology

[29]. Follow up education varied in frequency from weekly, monthly, to 1 year. Mode of follow up education was either by telephone or in person [27, 28, 30].

Outcome measures

The 4 acceptable studies included one or more of the following outcome measures: arm volume via calculated formula or arm circumference, quality of life via the Functional Assessment of Cancer Therapy-Breast (FACT-B) or the Lymphedema Life Impact Scale (LLIS), and functional outcomes via the Disabilities of the Arm, Shoulder, and Hand (DASH), LLIS, or the Subject Perception of Post-operative Functional Impairment of the Arm (SPOFIA) (Table 3). Although Bozdemir 2021 demonstrated significant reduction with arm circumference, volume was not calculated [19]. Clinically, arm circumference by itself is not considered a valid and reliable diagnostic method to detect BCRL in those at risk [31]. In 2 studies, improvement in quality of life was statistically significant as measured by the FACT-B ($p = 0.048$ at 6 months) and by the LLIS ($p = 0.007$ at 3 months) [17, 20]. Additionally, functional improvement was statistically significant at 3 months follow up in 2 of the acceptable studies as measured by the DASH ($p \leq 0.05$), SPOFIA ($p \leq 0.05$) [19], and the LLIS ($p = 0.024$) [20]. One complication following treatment for BC is post-operative wound infection, which may be a contributing factor to the development of lymphedema [32]. Only one study reported the incidence of postoperative surgical wound infection and adherence to the BCRL education. Infection was insignificant ($p = 0.26$), and adherence rates (65%) were similar in both the intervention and control groups [18]. Notably, those participants who received BCRL education and requested follow-up sessions with a physical therapist were fully adherent to the post-operative education provided. BCRL education was not examined as an individual intervention in all studies except one; rather, it was a component of the overall plan of care. Therefore, the effect of education on these outcome measures was not specifically examined. In order to determine the impact of BCRL education, knowledge acquisition as an outcome measure pre- and post-education needs to be assessed. Zhang (2020), a low-quality study, attempted to indirectly assess knowledge acquisition in patients with and those at risk for BCRL using the Exercise of Self Care Agency Scale (ESCA) [26]. This scale included 4 domains, one of which investigated level of health knowledge. The problem-based learning intervention group was instructed to perform self-massage, ROM, and utilization of a compression sleeve. Although the ESCA scores demonstrated significant improvement ($p < 0.05$) at discharge, 1 month, and 3 months post discharge, learning was not directly assessed. This result infers that adherence to self-care practices reflects knowledge acquisition.

Table 3 Outcome measures and results

Author, year, timing of education, sample size (N=)	Arm volume	Quality of life	Function	Complications	Adherence	Other outcomes
Acceptable						
Bland, 2019, Post-operative education (N = 161, Intervention n = 79)	Measured but results not presented	FACT-B 6 months $p = 0.048^*$	Not an outcome	Not an outcome	Not an outcome	Incidence of BCRL Intervention group: 33 within 1 yr (52%); 6 > 1 yr (9%) Control group: 26 within 1 yr (47%) 7 after 1 yr (13%) Intervention group: greater number of SNB ($p = 0.002$) and ALND
Simoncini, 2017, Post-operative education (N = 161, Intervention n = 79)	Circumferential Calculated arm volume formula Change 0.7 (5.3) $p = 0.69$	FACT-B $p = 0.65$	DASH $p = 0.81$	Surgical wound infections 12.7% $p = 0.26$	65.5% $p = 0.92$	N/A
Bozdemir, 2021, Post-operative education (N = 58, Intervention n = 29)	Arm circumference Right arm circumference > left $p < 0.05^*$ significant	Not an outcome	DASH $p < 0.05^*$ SPOFIA $p < 0.05^*$	Not an outcome	Not an outcome	N/A
Omid, 2020, Education for women with BCRL (N = 105, Intervention groups n = 35 each)	Not applicable	Persian version of the LLLS (group education) 3/12 significant improved QoL over time $p = 0.007^*$	Part of Persian version LLLS (group education) Reduced impairment Significant over time $p = 0.024^*$	Not an outcome	Not an outcome	N/A
Low						
Paskett, 2021, Pre-operative education (N = 554, Intervention n = 312)	Arm circumference No difference 12/12 - 0.04; 95% CI, - 0.97 to 0.88; $p = 0.93$ 18/12 0.34; 95% CI - 0.97 to 1.64; $p = 0.61$	Not an outcome	Not an outcome	Not an outcome	Sleeve/gauntlet use and exercises 50% performed breathing/lymph flow, stretching, and strengthening ex as instructed 31% wore elastic garments as prescribed No association with sleeve use at 6/12 and lymphedema rates (OR 0.74; 95% CI, 0.40 to 1.36; $p = 0.33$	N/A
Naughton, 2021, Pre-operative education (N = 547, Intervention n = 309)	Limb volume No difference in preventing LE $p = 0.37$	FACT-B + 4 $p = 0.88$ at 18 months not significant African American patients had better emotional functioning $p = 0.0335^*$	Not an outcome	Not an outcome	Adherence to the LEAP exercises 50% and 31% wore the compression garment as prescribed due to lack of time and perceived benefit	N/A
Singh, 2013, Pre-operative education (N = 72, Intervention n = 41)	Not an outcome	FACT-B 105.42 (18.3) Change 1.92 (16.21) $p = 0.43$	DASH 18.3 (18.7) Change 4.76 (16.65) $p = 0.27$	Not an outcome	Not an outcome	N/A
Cho, 2012, Pre-and post-operative education (N = 145, Intervention n = 58)	Arm Circumference $p = 0.0097^*$	Not an outcome	Postmastectomy Activity Scale $p \leq 0.0001^*$ 4.34 (95% CI 4.21-4.49) T1 T2 - 5.12 (95% CI: 4.91-5.34)	Not an outcome	Adherence to wearing the gown and increased exercise $p = 0.039^*$	N/A

Table 3 (continued)

Author, year, timing of education, sample size (N =)	Arm volume	Quality of life	Function	Complications	Adherence	Other outcomes
Koelmeyer, 2020, Post-operative education (N = 20, Intervention n = 20)	L-Dex (> +6.5 defines as lymphedema) 25% had an increase of > +6.5 in 3 months	Lymphedema Symptom, Intensity and Distress Survey Arm version Decreased by 0.4 out of 10.0 (95% CI 0.1 to 0.7) over 6 months $p < 0.05^*$	Incidental and planned Exercise Questionnaire No increase in total Physical activity but there was an increase of 2.8 h per week (95% CI 0.4 to 5.2) $p < 0.05^*$ of planned exercise over 6 months	Not an outcome	Adherence to measuring 3 times per week 74% (SD 24; range 33 to 11) during 3 months	N/A
Zhang, 2020, Post-operative education (N = 85, Intervention n = 43)	Circumferential	Chinese version FACT-B Significant at 3 months $p < 0.05^*$	Not an outcome	Not an outcome	Not an outcome	N/A
Lu, 2015, Post-operative education (N = 1217, Intervention n = 672)	Circumferential > 2 cm difference	Not an outcome	Not an outcome	Not an outcome	Not an outcome	N/A
Cansiz, 2021, Education for women with BCRL (N = 44, intervention n = 44)	Limb volume calculated (p = 0.000)* Bioimpedance L-Dex no final data due to Covid-19	Adaptation to Chronic Illness Scale (p = 0.001)* Patient Activation Measure (p = 0.000)*	Katz Index of Independence in Active Daily Living Scale (p = 0.018)* DASH (p = 0.000)*	Not an outcome	Not an outcome	N/A
Liu, 2021, Education for women with BCRL (N = 41, intervention n = 40)	Limb circumference Significant lower at 4 months follow up $p = 0.006^*$	Not an outcome	Not an outcome	Not an outcome	Not an outcome	Breast cancer and lymphedema Symptom experience index Significant changes in functional, social, emotional, and psychological and self-perception among 5 test points (p ≤ 0.05)* No difference in sleep and sexuality (p > 0.05)
Ridner, 2020, Education for women with BCRL (N = 109, Intervention n = 47)	Bioimpedance No significant difference Cohen's d = +0.36	LSIDS-A no significant difference in reduction of symptoms effect size = 0.05–0.28; $p > 0.05^*$	Quick DASH No statistical difference $p > 0.05$ Effect size pamphlet group – 0.19 greater increase in function/wellbeing than web-based group +0.30	Not an outcome	Pamphlet group 62 (77.5%) completed their program Web-based multimedia 47 (58.8% completed their program $p = 0.011$ Web based took longer to do	N/A
Aringa, 2016, Education for women with BCRL (N = 23)	Limb volume (p = 0.01)* Tonometer	LYMQOL Discomfort (p = 0.00)* Sensory alternation (p = 0.02)* Swelling (p = 0.02)* Heaviness (p = 0.05)*	ULL-27 No significant change	Not an outcome	Perceived adherence for self-care (p = 0.01)*	Self-rated skin condition No significant difference

DASH Disability of Arm, Shoulder, and Hand questionnaire, SPOFA Subject Perception of Post-Operative Functional Impairment of the Arm, LLJS Lymphedema Life impact Scale, FACT B+4 Functional Assessment of Cancer Therapy Breast + Arm Morbidity Subscale, LSIDS-A Lymphedema Symptom and Distress Scale- Arm, BCRL breast cancer-related lymphedema, yr year, OR odds ratio, CI confidence interval, LE lymphedema

*Significant

Cho (2012) developed a 10-item investigator-designed questionnaire to assess participant knowledge about BC care [24]. The results indicated significantly higher knowledge scores for those who had education 0.36 (95% CI 0.30–0.40) compared to no education 0.11 (95% CI 0.07–0.15 $p=0.0001$). Overall, the results of these outcome measures could only infer that BCRL education played a role in improvements of quality of life, function, adherence to self-care practices, and early identification of lymphedema [17–20, 26]. Unfortunately, knowledge acquisition was not directly assessed in any of these studies.

Discussion/Summary

Based on the evidence appraised, this systematic review was unable to determine the optimal content, mode, and timing for BCRL education across survivorship. The BCRL educational content most consistently taught included definition of lymphedema, risk reduction practices, early signs and symptoms, and self-care management. Several low-quality studies in this review provided this information using previously developed BCRL educational material by the American Cancer Society Guidelines for Lymphedema, National Lymphedema Network, or Australian Cancer Council Lymphedema FACT Sheet [21, 22, 25, 28]. This information varies widely in depth and breadth but provides a general overview of BCRL physiology, pathophysiology, risk reduction practices, and interventions. These organizations provide an educational starting point for clinicians and survivors; however, universal guidelines for BCRL educational content do not exist. Most importantly, BCRL education should be individualized based on the survivors' needs and preferred learning styles. The educational session may be influenced by the phase and intensity of an individuals' cancer treatment plan, and therefore, the health care educator may adjust volume and content accordingly. Presently, healthcare providers independently determine what content to include, how to provide the education, and when to deliver it. Future research is needed to develop evidence-based BCRL recommendations on educational content, mode of delivery, and its timing.

Knowledge and retention assessment was not a primary or secondary aim of the reviewed studies. To determine effectiveness of BCRL education delivery, repetition and follow up of BCRL education over time may be needed for an individual to acquire and retain knowledge. Retention of knowledge and follow up with health care professionals may enhance early detection and treatment of BCRL [11]. Further research to assess the individuals' knowledge acquisition, understanding, and integration of the information received and the value of repeating education over time throughout survivorship are needed.

In the studies reviewed, psychosocial issues regarding the impact of BCRL education timing and volume of information provided were not assessed or discussed. Individuals diagnosed with BC may experience different treatment regimens throughout the trajectory of care, which results in varying demands and stresses. Additionally, it is well known that cancer treatments, especially chemotherapy, can lead to cancer-related fatigue and cognitive impairments that can influence knowledge acquisition [33, 34]. The negative impact of psychosocial issues across survivorship may influence the content, mode, and optimal timing of BCRL education. When developing BCRL education, healthcare professionals may consider balancing the volume of material, the time commitment required, and the individual's mental health [33]. Studies also reported that individuals have preferred learning styles; therefore, a multi-modal approach to BCRL education is indicated [12]. Healthcare professionals should ask individuals how they would like to receive the education. For example, some individuals prefer web-based education while others prefer one-on-one or in-person group education [12, 35]. Additionally, some individuals prefer the option of reading booklets and handouts prior to discussion [12, 35]. Finally, in these studies, the age of most participants ranged from 47 to 61 years. As age may influence the preference of delivery modes, it will need to be a consideration when designing a BCRL educational program. Further research is needed to explore all the factors contributing to an individual's ability to acquire knowledge.

Limitations

An overall limitation to this systematic review is the wide variability in methodology. Timing of BCRL education occurred pre/post operatively, or once BCRL developed. Content and volume of BCRL education varied across trajectory of BC care. Knowledge assessment and repetition of education was rarely included in the studies. Additionally, this systematic review included only English language publications from January 1, 2011 to December 31, 2021, which may have limited the authors' findings. Participant characteristics reflected a wide range of demographics and risk factors, which may influence the content, mode of delivery, timing of education, and total time required to deliver the patient education.

Impact for breast cancer health care professionals and survivors of breast cancer

Conclusion

Based on this systematic review, evidence suggests BCRL education should be provided at multiple time points along

the trajectory of care, with varying depth and breadth of content, and be provided via a multi-modal approach. The BC healthcare team should assess the survivors' BCRL knowledge and its acquisition and reinforce BCRL education appropriately. Education for individuals diagnosed with BC, at a minimum, should include a brief overview of BCRL, early signs and symptoms, a point of contact for questions, and early referral for intervention. Survivors, who are at high risk for developing BCRL, may need a more detailed educational approach emphasizing individualized risk reduction practices. Interventions for individuals with BCRL require a strong focus on self-management and self-efficacy. Future research needs to determine the most appropriate educational content, mode, time point, and follow up for providing BCRL education across the trajectory of survivorship.

Declarations

Conflict of interest The authors declare no competing interests.

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