



Breast cancer-related lymphedema patient and healthcare professional experiences in lymphedema self-management: a qualitative study

Huihui Zhao¹ · Yanni Wu¹ · Chunlan Zhou¹ · Wenji Li¹ · Xiaojin Li¹ · Liling Chen¹

Received: 23 March 2021 / Accepted: 23 June 2021 / Published online: 5 July 2021

© The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature 2021

Abstract

Purpose Breast cancer-related lymphedema (BCRL) self-management plays an important role in the lymphedema therapy. However, clinical knowledge of BCRL self-management remains minimal. This study aims to explore the experience surrounding lymphedema self-management from the perspectives of BCRL patients and healthcare professionals.

Methods Semi-structured interviews were implemented with BCRL patients and healthcare professionals. Audio-recordings of interviews were transcribed verbatim and thematic analysis was undertaken to analyze the interview data.

Results Thirteen BCRL patients (aged 34–65 years) and nine healthcare professionals (2 physicians, 4 nurses, and 3 lymphedema therapists) were interviewed. Five themes emerged from interviews with participants: knowledge-attitude-practice surrounding lymphedema self-management, emotional reactions towards lymphedema self-management, factors influencing lymphedema self-management, support needs for lymphedema self-management, healthcare professional support of BCRL self-management.

Conclusions This study showed knowledge-attitude-practice, feelings, influencing factors, roles, dilemmas, and support needs regarding BCRL self-management. Greater effort is required for healthcare professionals to strengthen the lymphedema self-management. Providing more educational program and holistic support, and strengthening the facilitators and controlling the barriers might benefit promoting lymphedema self-management. Likewise, healthcare professionals need adequate training to be able to meet patients' self-management support needs.

Keywords Breast cancer · Lymphedema · Self-management · Healthcare professional · Qualitative study

Introduction

Breast cancer-related lymphedema (BCRL) is a prevalent complication of breast cancer treatment and manifests as upper limb swelling [1]. Breast cancer patients who have undergone cancer treatments, such as sentinel or axillary lymph node dissection, radiation therapy, and/or chemotherapy, are easy to develop BCRL [2]. It is estimated that 14 to 40% of breast cancer survivors suffer from this complication [3], and BCRL may develop several days to 20 years after surgery [4]. BCRL is a chronic condition that may lead to lifelong impairment of the affected upper extremity [2, 5]. BCRL has a

significant negative impact on physiologic and psychological well-being [5, 6]. Therefore, more attention should be paid to the management of BCRL in order to improve the patient's health-related quality of life.

Patients with BCRL may experience various physical symptoms (e.g., pain, swelling, numbness, heaviness, and limitation of movement) and psychological issues (e.g., depression and body image distress) [7]. In addition, they also encounter various challenges in their lives because of BCRL, such as daily life impact (e.g., restrictions on personal life), social impact (e.g., social withdrawal and isolation), financial impact (e.g., treatment costs), and work impact (e.g., work return and performance) [7–9]. Both of these may negatively affect their abilities to fulfill the roles attributed to them in the family and society [10]. Hence, it is essential to provide enough supportive care to BCRL patients. However, current social awareness for BCRL is still limited [11]. Insufficient awareness and knowledge for BCRL were found in both BCRL patients and healthcare professionals [11]. Evidence

✉ Chunlan Zhou
495837129@qq.com

¹ Nanfang Hospital, Southern Medical University, NO.1838
Guangzhou Avenue North, Guangzhou, Guangdong 510515,
People's Republic of China

showed that healthcare professionals considered BCRL less serious than breast cancer and they trivialized the influence of BCRL [8]. Currently, BCRL is an incurable but manageable condition; it requires therapist-delivered treatment. Moreover, it is of great significance for BCRL patients to engage in lifelong lymphedema self-management to control lymphedema symptoms and slow the progression of lymphedema [12]. Supporting lymphedema awareness can strengthen patients' self-management of BCRL, which may contribute to lower lymphedema grades and fewer infection [11].

An increased emphasis has been placed on the importance of active self-management in prior literature [13]. Self-management is defined as the individual's ability to manage one's own chronic condition, including its symptoms, physical and psychosocial consequences, and treatment, and integrate this management into daily routine to achieve an optimal quality of life [14]. While self-management plays an important role in lymphedema therapy, current self-management regimens are labor intensive, time-consuming, and never-ending, representing a huge burden for BCRL patients [15]. The challenge of lymphedema self-management is multi-factorial and includes medical management (managing symptoms/treatment), role management (relationships with healthcare providers/family members/friends), and emotional management (managing emotions/positive self-image and preparing for an uncertain future) [16]. It has also been observed that patient adherence to prescribed lymphedema self-management activities was associated with achieving and maintaining successful treatment outcomes [17]. As reported in the literature, BCRL self-management adherence rates are sub-optimal, ranging from 28 to 69% [18]. Poor compliance with BCRL self-management may lead to progressive swelling and trophic skin changes, resulting in a poor quality of life. Therefore, it is necessary to understand the issues and challenges surrounding patient self-management, thereby taking actions to optimize promoting strategies to strengthen lymphedema self-management.

Self-management support is an effective disease management strategy that provides patients with educational and supportive interventions to increase their skills and confidence in the management of their chronic condition [16]. Providing self-management support to BCRL patients requires identifying their self-management needs. However, this is currently poorly addressed in the literature [10, 19]. A published qualitative study explored breast cancer survivors' views on lymphedema self-management support needs; patients mentioned that they needed social support, resources for self-care activities, and self-advocacy [19]. Another qualitative study, which investigated the lived experiences of patients with BCRL, found that the supportive care needs of BCRL patients were physical, psychosocial, medical, and financial in nature [10]. A few qualitative studies have evaluated patient perceptions of BCRL self-management [4, 12]. A previous study about the patient perception of success and benefit in the self-management of BCRL

found that patients had different degrees of acceptance and adjustment to life with BCRL and identified seven enablers and blocks to BCRL self-management [12]. Similarly, a prior study reported that physiologic, psychosocial, and psychological factors were barriers to successful BCRL self-management [4].

Despite a current body of literature that focuses heavily upon lymphedema self-management, little is known about the perspectives of patients and healthcare professionals on this topic. It is well known that healthcare professionals play a significant role in the treatment of BCRL, in particular by teaching patients lymphedema self-management methods [20]. Healthcare professionals can also provide social support to assist individuals in BCRL self-management. Limited personal knowledge about lymphedema self-management may impede the ability for healthcare professionals to provide better management and support. Not understanding healthcare professionals' views on BCRL self-management limits the ability to devise strategies for overcoming the challenges that they face when supporting self-management. Moreover, prior research found that different views and expectations on self-management support between patients and healthcare professionals might cause tensions between them [21]. Therefore, in order to fill these gaps, a deeper understanding of the experience of patients and healthcare professionals surrounding lymphedema self-management is needed, which may contribute to the development of targeted and effective strategies for enhancing BCRL self-management.

The purposes of this qualitative study were to (1) further explore patient perspectives on lymphedema self-management, including the experiences, knowledge, behaviors, motivators, barriers, and support needs during lymphedema self-management, and (2) gain insight into healthcare professionals' attitude towards, challenges with, and role in lymphedema self-management.

Methods

Study design

This qualitative study, with phenomenological approach, was conducted following the Consolidated Criteria for Reporting Qualitative Research (COREQ) [22, 23]. Phenomenological approach is a strategy which focuses on giving a comprehensive description of a phenomenon with regard to lived experience [22].

Setting

The current study was performed in the breast surgery department of a 3000-bed tertiary hospital in Guangzhou, China, from September to November 2020. There was an established lymphedema therapy center in the department.

Participants

Purposive sampling method with maximum variation was adopted in this study. The inclusion criteria for BCRL patients were as follows: (1) age over 18 years; (2) diagnosed with BCRL and prescribed a self-management program by a certified lymphedema therapist; (3) voluntary participation. Patients were excluded if they were cognitively impaired or were unable to communicate verbally unaided in Chinese. BCRL patients in this department were outpatients or inpatients who were receiving targeted therapy or chemotherapy. Healthcare professionals were included if they had more than 5 years of work experience in the breast surgery department and were willing to participate. Research ethical approval for this study was obtained from the ethical committees of the hospital, and written informed consent was signed by all participants.

Data collection

Participants who met the inclusion criteria were invited to participate in semi-structured interviews. Patients were interviewed according to the following interview guide: “How do you understand lymphedema self-management (namely take care of yourself at home)?” “please tell me your lymphedema self-management regimen?” “please explain your experiences and feelings about lymphedema self-management?” “please describe your experiences regarding the barriers and facilitators that influence lymphedema self-management?” “please tell me what kind of support you received during lymphedema self-management?” “please tell me what kind of support you need to perform lymphedema self-management?” For healthcare professionals, the interview guide included the following: “what is your opinion of and attitude towards lymphedema self-management?” “could you tell me what you have done and what you will do about lymphedema self-management?” “what challenges/ barriers and facilitators have you experienced while assisting patients with lymphedema self-management?” Patients were interviewed via telephone or face-to-face at the department. Healthcare professionals were interviewed face-to-face in a private room at the department. Code names were assigned to each participant instead of their real names. To minimize bias, a trained female researcher (Huihui Zhao) who was not part of the breast cancer department staff conducted the semi-structured interviews. Each interview was digitally audio-recorded and lasted from 20 to 40 min. Participant recruitment was finished when data saturation was achieved, which was when no new information emerged [24].

Data analysis

Audio-recordings of interviews were transcribed verbatim by one researcher (Huihui Zhao). Data analysis was performed using thematic analysis [25]. First, transcripts were read

independently by three researchers (Huihui Zhao, Chunlan Zhou, and Yanni Wu) to have an overall understanding of the text. They read the full text for several times and immersed themselves in the data. After identifying the units of the analysis and extracting the key meanings, the initial codes of the data were generated. Then, the results of the analysis were compared and discrepancies were solved through group discussion with three other researchers (Wenji Li, Xiaojin Li, and Liling Chen). Subsequently, these codes were organized according to the relationship between different codes to searching for themes. Finally, all elements were categorized into main themes and theme names were identified by research team. Data analysis software was not used in this study.

Rigor

This study is reported in accordance with the COREQ. To enhance the dependability of the study, any disagreement of the design, methods, data analysis, and results was all discussed in the research team until a concordance was reached. During the data analysis, all the participants' points of view were taken into account and all data were analyzed in a team-based fashion. To guarantee authenticity of the study, all categories were supported by participant quotations. To establish transferability of the study, clear descriptions of the sampling methods, inclusion criteria, exclusion criteria, and participant characteristics were provided.

Results

Demographics

In total, 13 BCRL patients and 9 healthcare professionals were enrolled and interviewed. Participant demographics are presented in Table 1.

Themes

Five themes were identified regarding the experience of patients and healthcare professionals with lymphedema self-management: theme (1) knowledge-attitude-practice surrounding lymphedema self-management; theme (2) emotional reactions towards lymphedema self-management; theme (3) factors influencing lymphedema self-management; theme (4) support needs for lymphedema self-management; theme (5) healthcare professional support of BCRL self-management. Themes, subthemes, and exemplar quotes from participants are shown in Table 2. A graphical representation of the relationship between the themes is presented in Fig. 1.

Table 1 Demographic characteristics of participants

Variable	Frequency (%)
Breast cancer-related patients' characteristics (n=13)	
Age (years)	Mean 50.3, SD (8.7), range (34–65)
Gender	
Male	0 (0.0)
Female	13 (100.0)
Occupational status	
Employed	5 (50.0)
Unemployed	5 (50.0)
Education level	
Primary school	4 (30.8)
Middle school	5 (38.5)
High school	2 (15.4)
College or above	2 (15.4)
Marital status	
Married	13 (100.0)
Single/divorced/widowed	0 (0.0)
Family monthly income (Chinese yuan)	
<3000	1 (7.7)
3000–5000	7 (53.8)
5001–10,000	4 (30.8)
>10,000	1 (7.7)
Residence	
Urban	10 (76.9)
Rural	3 (23.1)
Type of surgery	
Modified radical mastectomy	13 (100.0)
Treatments received after surgery	
No	0 (0.0)
Yes, chemotherapy	13 (100.0)
Yes, radiation therapy	7 (53.8)
Yes, targeted therapy	1 (7.7)
Yes, endocrine therapy	3 (23.1)
Lymphedema staging	
0	0 (0.0)
1	5 (38.5)
2	6 (46.2)
3	2 (15.4)
Location of the lymphedema	
Whole arm	11 (84.6)
Hand	2 (15.4)
Lymphedema side	
Left	4 (30.8)
Right	9 (69.2)
Time since lymphedema diagnosis, month	Median 8, 25–75% percentiles (4.5–17.5)
Healthcare professionals' characteristics (n=9)	
Age (years)	Mean 38.8, SD (6.5), range (30–53)
Gender	
Male	1 (11.1)
Female	8 (88.9)

Table 1 (continued)

Variable	Frequency (%)
Function	
Doctor	2 (22.2)
Nurse	4 (44.4)
Lymphedema therapist	3 (33.3)
Years in profession	
2–5 years	1 (11.1)
5–9 years	4 (44.4)
10–19 years	4 (44.4)
Education level	
Bachelor degree	4 (44.4)
Master degree	3 (33.3)
PhD degree	2 (22.2)

Theme 1 Knowledge-attitude-practice surrounding lymphedema self-management

Lymphedema self-management knowledge Knowledge is the foundation of action. However, some patients (4/13) felt that they did not have a good understanding of lymphedema self-management and two reported that their family caregivers were also not knowledgeable. They recalled receiving lymphedema education to learn more about lymphedema self-management, such as the definition of self-management and self-manual lymph drainage (MLD) methods.

I don't know much about lymphedema self-care. I didn't do it according to the prescribed self-management program. I don't understand what self-management is. Please tell me, I really don't understand [Patient, 13]

Attitude towards lymphedema self-management Most patients (7/13) had a relatively good acceptance and adaptability towards lymphedema self-care. They realized that they should take responsibility for their own body, whether that be active or passive. They were willing to keep practicing lymphedema self-management to control lymphedema better even though it was troublesome.

There were several times that I wanted to give up, but I told myself I must do it (self-management). I will persist in undertaking it. I want to become healthy physically again. [Patient, 13]

However, there was one patient who misunderstood lymphedema self-management. She complained that self-management was not a form of lymphedema treatment and that better methods for curing lymphedema should be provided to her.

At present...at present you only have this method. What you have done just plays a role in relieving symptoms, rather than curing lymphedema. Is this a form of therapy? No, it just relieved...relieved lymphedema, relieved, without achieving the therapeutic effect [Patient, 4]

Self-management behaviors A majority of the participants (11/13) said that they performed lymphedema self-management activities. Activities performed by patients included the following (frequency goes from high to low): exercise (rehabilitation exercises, walking, Tai Chi, square dancing), limb elevation, compression sleeve, self-MLD, compression bandages, and intermittent pneumatic compression (IPC). Two patients bought massage machines to do pneumomassage at home. Despite a high level of engagement with lymphedema self-management, patients generally did not perform it according to the recommendations provided by the lymphedema therapist. Some key measures, such as self-MLD and compression bandages, were seldom performed, or were practiced at a reduced frequency.

After the first phase of CDT, I seldom wore bandages, maybe once a month. I just wore a compression sleeve every day. [Patient, 11]

Table 2 A full table of themes, subthemes, and exemplar quotes from participants

Themes	Subthemes	Examples of quotes
1. Knowledge-attitude-practice surrounding lymphedema self-management	Lymphedema self-management knowledge	<p>“She (lymphedema therapist) mentioned it (self-MLD) before, but she did not emphasize how to do it, so I don’t know.” [Patient, 1]</p> <p>“Anyway, I just engaged in self-management measures in my own way. She (lymphedema therapist) didn’t tell me what kind of compression garment should be used, so I just bought one on Taobao and I don’t know whether it suits me.” [Patient, 9]</p> <p>“I don’t know how to do self-MLD, I think my method that I massaged myself was wrong. My husband knew that my arm was swollen and he massaged me with great force, which made me feel very painful.” [Patient, 2]</p>
	Attitude towards lymphedema self-management	<p>“For now, I will stick to do it (self-management). My arm is swollen, there is no other way to cure it, so I have to do it (self-management).” [Patient, 1]</p> <p>“With my arm like this, I have always insisted on doing it (self-management). If I do not undertake self-management, I will not be able to go on with my life, it (lymphedema) affects me a lot.” [Patient, 2]</p> <p>“My own body, I must...In the past, I thought that... I was young and didn’t pay much attention to it. Now... I must take care of myself better.” [Patient, 3]</p> <p>“Nobody wants to wear it (sleeve). It made me feel uncomfortable. It’s uncomfortable, but I still have to wear it. If you don’t insist, it has no effects on controlling lymphedema. Every morning when I wake up, the first thing I do is to wear it. I have formed a habit of it.” [Patient, 6]</p> <p>“I can’t stand my arm swelling like this, I must do it.” [Patient, 7]</p> <p>“I do not have any views on lymphedema self-management, it is not tiring. I think I can stick to it.” [Patient, 11]</p>
	Self-management behaviors	<p>“Sometimes, I wear the compression sleeve and massage myself. When I am resting, I usually elevate my arm. But I seldom do exercises.[Patient, 1]</p> <p>“After the first phase of CDT, I did not conduct self-MLD or wear bandages, and I seldom wore a compression sleeve. I just did exercises and elevated my arm during bed rest sometimes.” [Patient, 2]</p> <p>“After the first phase of CDT, my lymphedema self-management is to wear bandages or a compression sleeve and go to Tai Chi every day. I also elevated my arm during bed rest sometimes”[Patient, 3]</p> <p>“I wear a compression sleeve and do exercises almost every day. I go for a walk in the park every morning. At night, I elevated my arm with a pillow during bed rest.”[Patient, 5]</p> <p>“Over the past few years I have insisted on wearing the compression sleeve every day, no day falls. I wear it for the whole day and take it off when I go to bed at night. Besides wearing the compression sleeve, I also do rehabilitation exercises twice a day, or go to square dancing in the morning.”[Patient, 6]</p> <p>“After CDT treatment, I wear bandages one or two days a week. In the evening, I wear them (bandages) after taking shower. As for the compression sleeve, (the frequency of wear compression sleeve) almost four days a week. In addition to these measures, I seldom take other self-management measures (e.g. massage).”[Patient, 7]</p> <p>“After CDT treatment, I seldom wear bandages, I just wear a sleeve sometimes, but I am lazy, I do not wear it every day.” [Patient, 8]</p> <p>“In general, I wear a sleeve at night. Sometimes, I massage myself or do exercises.” [Patient, 9]</p> <p>“For me, when I have time I will perform self-management, including doing exercises, wearing sleeves and massage, but I seldom engage in it.” [Patient, 12]</p> <p>“In general, I wear a sleeve and receive intermittent pneumatic compression therapy. I bought an intermittent pneumatic pressure therapy apparatus at home. I wear the sleeve for 7-8 hours a day and undergo intermittent pneumatic compression therapy for 3-4 times a day.” [Patient, 13]</p>

Table 2 (continued)

Themes	Subthemes	Examples of quotes
2. Emotional reactions towards lymphedema self-management	Anxious	“I measured my arm circumference several times a day, but it was still as big as before. I just wanted to know whether my arm can be recovered.” [Patient, 11]
	Troublesome	“I think it (self-management) is troublesome, troublesome.” [Patient, 1] “I do not want to wear bandages and a sleeve, I feel very annoyed (crying).” [Patient, 11] “I think it (self-management) is very troublesome.” [Patient, 7] “So tired, I just feel so tired because of lymphedema self-management.” [Patient, 13]
	Hopelessness	“What makes me feel hopeless is...self-management can not cure it (lymphedema). Now I do not know what to do.” [Patient, 6] “Well, for BCRL, nothing can be done about it.” [Patient, 1] “Lymphedema self-management is a life-long process, I felt hopeless.” [Patient, 13]
	Desire	“I just want to know if there is any way to cure it, can you tell me how to treat my arm?” [Patient, 2] “I hope that healthcare professionals could have a better way to treat it. Just like taking a course of fast-acting tablets, my arm could be as normal as before.” [Patient, 7] “I hope that there is a better therapy to cure lymphedema.” [Patient, 1] “What I only hope is that we can cure lymphedema as soon as possible.” [Patient, 6] “I want to return to my life before lymphedema.” [Patient, 11]
3. Factors influencing lymphedema self-management	Sense of self-value	“Although my family members help me wear the bandage...sometimes they are not at home, or because of other reasons they did not help me with it. I should learn to wear it by myself. It’s more convenient that I wear it by myself. It’s impossible for every family member to learn it, I can also do it by myself.” [Patient, 3] “I’m just afraid that I can’t take care of myself due to BCRL. I’ll be sad if it comes to that point. I am an independent person.” [Patient, 6] “Now, I have returned to work because I want to live a normal life as before. More importantly, when I do my work I need to elevate my arm, which can relieve my symptoms.” [Patient, 11] “After breast cancer surgery, I returned to work. Lymphedema self-care has a positive impact on my arms, so I can work as capably and dependably as before (prior to BCRL).” [Patient, 12]
		Fear of aggravation
	Discomfort	“It’s too hot in the daytime, isn’t it? So, I...took it (bandage) off and I didn’t wear the sleeve. It’s too hot, I didn’t wear it. If I wear it, my skin will become red with sweat, you know.” [Patient, 2] “It’s so hot in summer, I can’t stand it. I can not stay in the air-conditioned room all the time. I am waiting for the weather to get colder, and then I may wear it again.” [Patient, 3] “I have bought bandages, but I could not stand wearing it, I just wore it sometimes. I left it out when I felt pain. Usually, I wore it at night and I left it out in the mid-night.” [Patient, 11]
		Restricted function

Table 2 (continued)

Themes	Subthemes	Examples of quotes
		“When I wore the sleeve, all my fingers became swollen, which made it inconvenient for me to perform housework and work activities.” [Patient, 12]
	Lack of time and energy	“I don’t have time to do it (self-management), because I go to work from morning to night.” [Patient, 11] “I’m busy all the time. I rarely have leisure time, I rarely have leisure time.” [Patient, 12] “For some patients, they need not to return to work because of the disease, so, they may have enough time to undertake self-management. For the patients who return to work, it is difficult for them to undertake self-management because of the nature of their job.” [Healthcare professional, 8] “If patients are busy with work, they will not have enough time to conduct self-care.” [Healthcare professional, 1]
	Lack of skills and knowledge	“In general, I wear the bandages by myself, I can wear it by myself, but I am unskillful. The night before yesterday, when I wore it, I felt it was so tight, and all my arm was numb.” [Patient, 7] “I don’t know how to massage by myself, so I seldom do it.” [Patient, 2] “I can’t wear bandages by myself, so I seldom wear it.” [Patient, 4] “I don’t know how and what I should do regarding lymphedema self-management.” [Patient, 9] “Lymphedema self-management is associated with the patient’s learning ability. If patients have sufficient knowledge and skills, they may have a better self-management (outcome).” [Healthcare professional, 1] “Patients’ skills and knowledge of lymphedema self-care is an important factor. Some patients have poor skills and insufficient knowledge, so they can’t understand it.” [Healthcare professional, 7]
	Family assistance	“My family is so busy that it’s hard for them to help me.” [Patient, 5] “My husband is busy with work. My children are young. It’s difficult for them to provide assistance to me.” [Patient, 7] “My family is so busy, I have to deal with it (self-care) myself. Furthermore, I need to fulfill my family responsibilities.” [Patient, 12] “My husband is busy with work and he’s away lot. My children are still at school. In general, I stay at home alone.” [Patient 13] “In general, I always do everything by myself. My daughter and son-in-law are busy with their work, and they don’t have time to take care of me. I don’t want to bother them with my problems. Unless one day I can’t walk and I had to stay in bed, I will need them to take care of me.” [Patient, 8]
	Self-management effects	“When I wore the bandages, it helped with the swelling of my arm, but it made the back of my hand become swollen.” [Patient, 11] “I bought a sleeve, but I think there was no improvement in my lymphedema symptoms. When I put on it, my swelling decreased. When I took off it, my arm became swollen again.” [Patient, 12] “When I wore the sleeve or bandages, the swelling in my arm lessened, but my fingers become swollen. So I think there is no need to wear it.” [Patient, 2] “I engaged in self-care for a long time, but I don’t think it works.” [Patient, 4] “Sometimes...if the symptoms were not improved, I wore the sleeve with a reduced frequency.” [Patient, 5]
	Financial restraints	“During the treatment, many patients may give up the treatment because of the financial restraints. For some patients, the price of compression hosiery is too high to buy it.” [Healthcare professional, 6]
	Patient characteristics	“It is easier for young patients to learn about self-management skills. Of the patients we followed, most of (the ones) who had good lymphedema self-management skills were young people. For some old patients they were unwilling or unable to learn it and tended to rely on their family.” [Healthcare professional, 8]

Table 2 (continued)

Themes	Subthemes	Examples of quotes
4. Support needs for lymphedema self-management	Severity of the lymphedema	“The characteristics of patients are different, if the patient is a negative person, she will not conduct self-management well.” [Healthcare professional, 3]
		“I think self-management ability is related to patient age.” [Healthcare professional, 4]
	Psychological support	“At present I think it is unnecessary for me to conduct self-care, as it’s nothing serious. If it gets any worse, I will engage in self-care seriously” [Patient, 7]
		“I do not feel any discomfort at all, it (my arm) is just swollen.” [Patient, 9]
Instrumental support	“I hope that there will be someone who can understand my pain and provide psychological comfort for me.” [Patient, 6]	
	“For the method of wrapping the bandages, I still want to... um...be trained about it, to be more skillful, and then I can wrap it by myself.” [Patient, 8]	
Social support	“Oversight from healthcare professionals and family members is needed. Although follow-up was conducted in our department, improvements need to be made. For example, we didn’t conduct follow-up visits regularly and we didn’t perform encouraging measures to improve patient adherence to self-care.” [Healthcare professional, 4]	
	“During the process of lymphedema self-care, when I encounter problems that I can not solve by myself, it is difficult for me to get assistance from healthcare professionals. Where I live is far away from the hospital that has a lymphedema therapist. Many medical resources were not available.” [Patient, 3]	
5. Healthcare professional support of BCRL self-management	The attitude of healthcare professionals towards lymphedema self-management	“If the cost of the lymphedema treatments, including the cost of self-care supplies and lymphedema therapist therapy, can be covered by health insurance. I think there will be more patients have access to the lymphedema treatments and willing to continue to undertake self-care.” [Healthcare professional, 6]
		“I live in the countryside, there is no BCRL treatment therapy in the local hospital. I don’t have time to go to the hospital which has advanced treatment methods for BCRL.” [Patient, 9]
	The role of healthcare professionals in lymphedema self-management	“So...I think follow-up is important.” [Healthcare professional, 7]
		“We should follow-up regularly to strengthen patients self-care.” [Healthcare professional, 5]
The role of healthcare professionals in lymphedema self-management	“Self-management must be important.” [Healthcare professional, 3]	
	“Patients’ lymphedema self-management is necessary.” [Healthcare professional, 5]	
The role of healthcare professionals in lymphedema self-management	“Um, actually, I don’t know much about it (lymphedema self-management). I feel like that I don’t know much about it.” [Healthcare professional, 3]	
	“During the lymphedema self-management process, first at all, we health professionals tell patient what lymphedema self-management is and how to conduct self-management. Then we evaluate their daily self-care measures and the effects of self-care to help maintain their health. If patients conduct self-care measures in the wrong way, we need to help them correct it in time and support them if they need it...Additionally, if there are better treatments, or new information, or updated knowledge, we will provide this to patients in time to achieve an optimal lymphedema self-management.” [Healthcare professional, 6]	
The role of healthcare professionals in lymphedema self-management	“A variety of health education for patients and their family caregivers were provided by us to promote self-management within the healthcare system. Furthermore, critical oversight was conducted to remind patients to undertake self-management.” [Healthcare professional, 3]	

Table 2 (continued)

Themes	Subthemes	Examples of quotes
	Healthcare professionals' dilemmas in lymphedema self-management	<p>“We provide health education for patients to help them undertake self-management at home. Additionally, we also play a reminder role through following-up with them.”[Healthcare professional, 2]</p> <p>“At present, I think it is difficult for us to promote lymphedema self-management. This is because physician engagement is not high enough. Some physicians mainly focus on the breast cancer treatments. For lymphedema self-management they rarely emphasize the importance of it, leading to decreased awareness of self-management.” [Healthcare professional, 4]</p> <p>“I think it (lymphedema self-management) is a dynamic process that needs continuous evaluation. However, as far as I know, what we conducted for patients is fragmented, rather than a complete management system. We need to formulate a systematic protocol of self-management and improve the self-management system.” [Healthcare professional, 9]</p>

This phenomenon was identified by one healthcare professional who said,

I just want my hands to be recovered. I have no other needs. I'm anxious, anxious. I want to achieve a quick symptom improvement. [Patient, 1]

Through the follow up, we found patients' lymphedema self-management behaviors were not so good. [Healthcare Professional, 6]

Troublesome Many patients (5/13) voiced lymphedema self-management was troublesome. They explained that lymphedema self-management is a complex and time-demanding process and that they needed to spend a good deal of time on it in their daily life, which made them feel annoyed and increased their psychological distress.

Theme 2 Emotional reactions towards lymphedema self-management

Anxious Some patients (2/13) were concerned about the lymphedema and wanted to control it quickly. Recognition that lymphedema is an incurable disease and a lack of symptom improvement and progression despite self-management were the main reasons for anxiety.

I do not want to continue self-management, I want to give up. I conduct it everyday, I am irritable, irritable. I think it is troublesome. [Patient, 5]

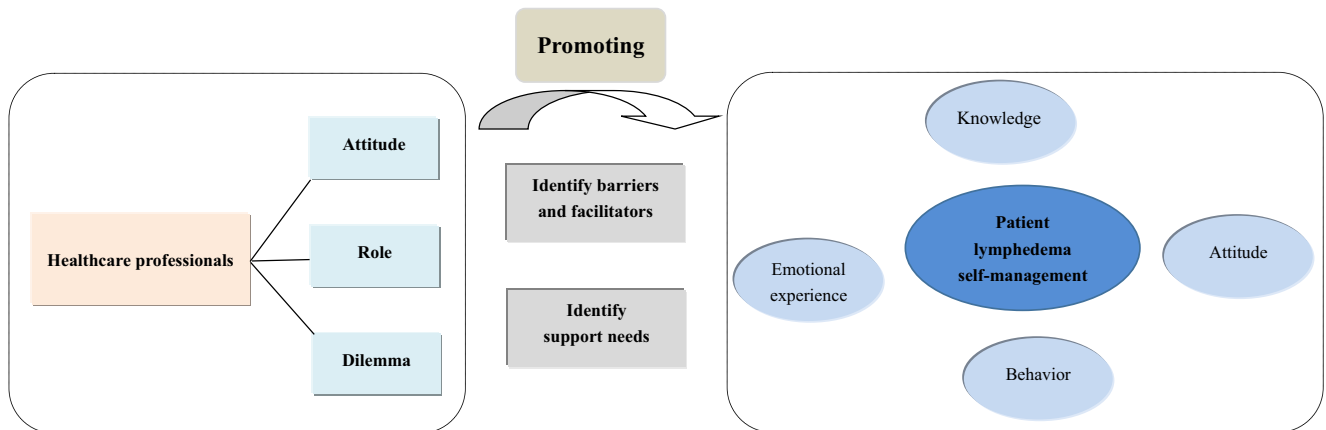


Fig. 1 Graphical representation of the relationship between the themes

Hopelessness Although self-management can control lymphedema, it cannot cure it. Some patients (4/13) felt hopeless because the effects of self-management did not meet their expectations. They stated that their arms became swollen again when they took off the sleeve or bandage. They were depressed because they had to live with lymphedema through lifelong self-care.

If I wear the bandage, my arm seems like normal, but when I take it off, my arm builds up again. Could it be non-recurrent through self-management? [Patient, 2]

Desire

Given the lifelong requirements of BCRL self-management, many patients (6/13) described their expectations for lymphedema treatment. They desired a new therapy that could cure lymphedema. They wanted to improve their health status and live a normal life.

I hope that healthcare professionals could provide me a better way to cure it, to relieve my pain. [Patient, 5]

Theme 3 Factors influencing lymphedema self-management

Motivators (sense of self-value, fear of aggravation, severity of the lymphedema, and patient characteristics (younger age, a positive attitude towards lymphedema self-management, strong self-discipline, and a high education level)) and barriers (discomfort, restricted function, lack of time and energy, lack of skills and knowledge, family assistance, self-management effects, and financial restraints) were identified according to statements by patients and healthcare professionals. Whether these factors were considered motivators or barriers is dependent on the individual's unique situation.

Sense of self-value Some patients (5/13) reported that they learned to deal with self-management as part of their daily life, for the reason that they still viewed themselves as an able person. They wanted to be independent and to show that they were still able to do many things with their bodies.

You know, if I discontinued self-management, I would be unable to engage in some activities of daily life such as eating and washing. I don't want to be taken care of

by others. Additionally, I also do housework everyday. I must learn to take care of myself, right? [Patient, 2]

Fear of aggravation Some patients (4/13) reported that they continued to perform self-management activities because they were afraid of exacerbating their lymphedema. They recognized the serious consequences of not taking care of their lymphedema (e.g., irreversible physical damage, altered physical appearance).

Now, I just hope that my swelling will be stable without changed symptoms. What I'm afraid of is the deterioration of swelling. It scares me to death, right? I'm afraid that my arm will become more swollen. [Patient, 2]

One healthcare professional shared the same opinion.

For some patients, they feel uncomfortable and want to be healthy. All of these may promote them undertaking self-care measures. [Healthcare Professional, 6]

Discomfort Some patients (4/13) stated that they felt uncomfortable (e.g., pain, numbness, itchy) when they wore a sleeve or bandage, especially during the summer. Two patients said that they felt very hot when they used compression garments in the hot weather, leading to a poorly used compression garments. Increased discomfort from sleeves/bandages decreased patient's compliance with self-care.

When I wore the bandage in the evening, I felt a pain in my arm, all my fingers were numb and my skin was itchy. It was uncomfortable, so I seldom wore it. [Patient, 7]

This factor was also identified by one healthcare professional.

Although there is relative more comfortable to wear sleeve than bandage, patients also experience discomfort caused by the sleeve, leading to poor compliance with self-care. [Healthcare Professional, 6]

Restricted function A few patients (4/13) reported that they experienced restrictions and negative impacts of lymphedema self-care on their daily lives and activities. The use of a sleeve

or bandage indirectly interfered with activities, such as household chores, bathing, taking care of children, and work.

I need to take care of my grandson. The sleeve restricted my movement if I wore it. It was inconvenient for me to take care of my grandson. I was afraid of getting it wet and things like that.... [Patient, 8]

Lack of time and energy Patients (3/13) and healthcare professionals (2/9) reported that time and energy constraints influenced self-management. They needed to deal with many things other than BCRL. Patients had to cope with and manage other chronic diseases or were busy with housework, work activities, or taking care of children. They therefore did not have enough time and energy to conduct appropriate lymphedema self-management.

I rarely used the bandage, I am very busy now. I need to take care of my grandson. In addition, I suffer from too many other diseases, such as diabetes and hypertension, and my neck and waist also hurt. I am more concerned about the diseases that cause pain. I don't have much time and energy to conduct lymphedema self-management. I pay little attention to it (lymphedema) now. [Patient, 8]

Lack of skills and knowledge Skills and knowledge are important to lymphedema self-management. Some patients (5/13) noted that they lacked the knowledge and skills required for self-care, especially with respect to bandaging and massaging. However, they rarely asked healthcare professionals for more educational training because they thought that the healthcare professionals were too busy. Two healthcare professionals (2/9) also identified a lack of skills and knowledge as barriers to lymphedema self-care, but did not realize that the reason why no help was sought was because the patients did not want to disturb them.

I can't wear it (bandage) well. Sometimes I felt that it was too tight to bear, and sometimes I felt that it was too loose. In a word, I can't wear the bandages by myself. I want to learn the skills from a lymphedema therapist, but they are so busy that I don't want to disturb them. [Patient, 8]

Family assistance Some patients (5/13) complained that they could not get enough support from their family regarding self-

care. They explained that their family was busy with work activities and most of their children were at school, so it was difficult to receive appropriate support from family. The patients therefore had to cope with self-management alone.

I can't conduct the self-MLD by myself. I can massage my own arm, but it's impossible for me to massage my back and neck. My husband is busy with work and my kids are at school. Nobody can help me. [Patient, 2]

Other patients (2/13) reported that they did not need family assistance. Because social conformity and collectivism are important in Chinese culture, they wanted to avoid burdening their families and preserve a harmonious relationship with their family.

I don't need (help) from my family anymore and I think what they have done was enough for me. I don't want to increase the burden on my family. [Patient, 6]

Self-management effects Some patients (5/13) stated that the effects of self-management influenced their positivity of undertaking self-management. They complained that there were only slow progressions or unimproved symptoms after performing self-management. They also noted that the use of bandages/sleeves resulted in swelling of other parts of their arm.

When I put on the compression sleeve or wore the bandages in the daytime, my fingers become swollen and my arm was still swollen without any improvement. If I did not use the sleeve or bandages, there was no increase in arm swelling, so I did not want to wear it. [Patient, 2]

One healthcare professional shared a similar opinion.

Whether or not self-management has an obvious effect also affects patients' motivation, doesn't it? [Healthcare Professional, 4]

Financial restraints One patient (1/13) expressed that she could not bear the costs of self-care. For example, she was not able to buy new sleeves and bandages, because they were expensive and not covered by health insurance. One healthcare professional (1/9) also said that the high cost of BCRL treatment is an economic burden on patients and leads to reduced compliance with lymphedema therapy.

It (the costs of compression hosiery) was so expensive for me and it was not covered by health insurance. I don't want to use it anymore. [Patient, 10]

Patient characteristics Healthcare professionals (4/9) stated that patient characteristics such as age, education level, attitude, and self-discipline may influence compliance with and the effects of lymphedema self-management. They indicated that younger patients, with a positive attitude towards self-management, strong self-discipline, and a high education level, may have a better understanding of and skills with self-management, leading to better lymphedema control.

For the patient who has strong self-discipline, she can completely undertake lymphedema self-management measures according to healthcare professional direction and she thinks that what healthcare professionals say is beneficial to the treatment of lymphedema. Besides self-discipline, I think that patient education level is also a factor. If a patient has a higher education level she may search for lymphedema self-management knowledge on the Internet to learn more about it. [Healthcare professional, 5]

Severity of the lymphedema According to the statements of patients (3/13) and healthcare professional (1/9), severity of the lymphedema may be seen as a motivator for self-management. Lymphedema severity is evaluated with circumferential tape measurements and an assessment of symptom severity. Patients explained that if they suffered from mild lymphedema with slight lymphedema symptoms, they might not focus on it. If the condition worsened, they might take self-management seriously.

For me, it (lymphedema) doesn't have significant negative impact on my life, so I do not pay attention to it. [Patient, 12]

One healthcare professional noted that if a patient had mild lymphedema, less importance would be attached to self-care.

If the patient has mild lymphedema, she may not care about it. If severe swelling occurs, the individual may attach more importance to it. [Healthcare Professional, 6]

Theme 4 Support needs for lymphedema self-management

Psychological support A few patients (2/13) reported that they hoped that healthcare professionals would provide psychological support for them, such as encouragement, comfort, and ways to reduce negative emotions due to their lymphedema. They emphasized that receiving psychological support from healthcare professionals would empower them to cope with self-management. They were more likely to listen to healthcare professionals.

I hope that the healthcare professionals will give us psychological guidance. It is better if the healthcare professionals provide us with some encouragement, comfort, or instruction. What healthcare professionals say is more convincing, because they are professionals. [Patient, 1]

Instrumental support A minority of patients (2/13) said that they had insufficient self-management knowledge and skills and that they wanted to receive instruction and information from healthcare professionals. They needed more tailored information about establishing a self-management daily routine and appropriate bandaging techniques.

For the lymphedema self-management, healthcare professionals are professional. I hope that they can provide me with instruction regarding how to self-manage during daily life. I really don't know it. In general, I just do it in my own way, I hope [the healthcare professionals] can provide me with information accordingly. [Patient, 13]

Social support Both patients (3/13) and healthcare professionals (4/9) indicated that social support was needed to improve compliance with lymphedema self-management. Such support included encouragement from peers, intensive follow-up by healthcare professionals, and the availability and accessibility of medical resources. Patients expressed that the encouragements about how other patients implemented different adaptive tasks would help them to practice self-management better. Both patients and healthcare professionals emphasized that follow-up evaluations were helpful for promoting self-management. Participants also talked about difficulties that reduced their access to better medical services, such as living a long distance from lymphedema therapy and the high costs of lymphedema self-management.

Uh...it is better...to establish a Wechat Group comprised of many other BCRL patients. In this way, we can

communicate with each other online, and I can learn self-care experience from other peers. Furthermore, general reminders (e.g., text messages) related to lymphedema self-care are necessary to remind us to conduct the self-care activities (e.g., exercise). [Patient, 1]

Theme 5 Healthcare professional support of BCRL self-management

The attitude of healthcare professional towards lymphedema self-management Healthcare professionals (3/9) stressed the importance of lymphedema self-management. They considered lymphedema self-management to be an important part of lymphedema treatment. The importance of self-management support with respect to CDT treatment, which is home-based and crucial for patients to control lymphedema, was particularly emphasized.

I think lymphedema self-care is important. It is necessary to strengthen self-management, because the second phase of CDT is mainly conducted in the patients' home, so the patients can't rely on us entirely. [Healthcare Professional, 4]

However, one healthcare professional reported that it was the nurse's duty to encourage patients to engage in a lymphedema self-management program, rather than the physician.

In fact, lymphedema self-management was mainly done by nurses. We physicians seldom did it. I think physicians are responsible for cancer treatments and nurses are responsible for lymphedema care. We should have a clear division of labor and do our own job well. [Healthcare Professional, 7]

The role of healthcare professionals in lymphedema self-management Healthcare professionals (4/9) said they serve as support providers, health educators, and supervisors of lymphedema self-management in order to motivate patients to cope with the self-management. They described themselves as working in the healthcare system to support patients to improve their lymphedema self-management. When patients alerted them to symptom exacerbation or consulted with these healthcare professionals, they facilitated further assessment and action as quickly as possible. Healthcare professionals also described themselves as key to providing health education and oversight of the self-management process. They taught patients lymphedema management options such as symptom self-monitoring, self-management skills, and a

healthy lifestyle. Irregular follow-up evaluations were conducted by them to remind patients to continue self-care.

We have provided patients with a platform that could be used by the patients to give feedback or consult us with their problems. Patients can learn lymphedema knowledge on the WeChat Official Platform and they can communicate with us through WeChat when they have problems with lymphedema self-management. For example, when an individual reports a symptom exacerbation, after teaching her to measure her arm circumference at home, initial assessment and instruction will be conducted to enable the patient to return to self-managing her health. If the patient's problem can not be solved through an online consultation, we will advise them to come into the lymphedema clinic for further treatment. [Healthcare Professional, 1]

Health educators must possess adequate lymphedema self-management knowledge. However, a few healthcare professionals (2/9) noted that healthcare professionals who were not lymphedema therapists were unfamiliar with lymphedema self-management and could not provide appropriate instruction to BCRL patients.

Only lymphedema therapists have an overall understanding of lymphedema self-management. Many other medical staff in our department were unfamiliar with lymphedema self-management. So, when patients go to a medical consultation, they may not be able to give patients the right guidance, which may mislead the patient in some way. [Healthcare Professional, 6]

Healthcare professionals' dilemmas in lymphedema self-management Healthcare professionals (3/9) identified several dilemmas that they faced while promoting lymphedema self-management, namely insufficient human resources, a lack of physician involvement, and incomplete self-management system. They explained that there was a lack of trained lymphedema therapists or lymphedema specialist nurses to manage BCRL in their department. They also mentioned that physicians paid little attention to lymphedema self-management, which had a negative impact on the patients' awareness of self-care. They also cited that the current lymphedema self-management system is fragmented and lacks a systematic protocol or flow, which needs to be improved upon.

On the other hand, the human resources, the number of the healthcare professionals who are responsible for

BCRL management are insufficient. Most the time, there is only one lymphedema therapist who undertakes lymphedema management, including lymphedema treatments, follow-up and so on. It is difficult for only one person to finish these things, which may have a negative effect on promoting lymphedema self-management. [Healthcare Professional, 6]

Discussion

This qualitative study provides an deep understanding of the perspectives of BCRL patients and healthcare professionals towards lymphedema self-management. The current study explored the myriad experiences of BCRL patients with regard to lymphedema self-management, including knowledge, attitude, behavior, emotional experience, influencing factors, and support needs. The attitude of healthcare professionals and the dilemmas that they faced in the promotion of lymphedema self-care and the support of self-management were also identified. Overall, these experiences provided a holistic view of the multi-faceted issues surrounding lymphedema self-management. Patient knowledge-attitude-practice and emotional experience were four important aspects of the implementation of lymphedema self-management protocols. Healthcare professionals supported self-management by identifying barriers, facilitators, and support needs to help patients better engage with self-management.

Our findings indicate that although most patients and healthcare professionals had a positive opinion towards lymphedema self-management, their self-management knowledge was insufficient. Moreover, there was a misunderstanding of lymphedema self-management among them. For patients, this lack of knowledge has a negative impact on their ability to implement self-management activities and perceive the benefits of treatment [12]. Knowledgeable healthcare professionals play an important role in facilitating lymphedema management [26]. However, those healthcare professionals who were not lymphedema therapists possessed insufficient knowledge of self-management, which coincided with the findings of prior work [27]. Therefore, additional lymphedema educational programs should be offered to improve both healthcare professional and patient knowledge about lymphedema self-management. Healthcare professionals should emphasize that lymphedema self-management is an important way to slow the progression of lymphedema. Moreover, this study found that physicians had a low sense of participation in the promotion of lymphedema self-management. This is because conservative treatments are still the primary therapies for BCRL in China and most of these treatments are conducted by lymphedema therapists (nurses). Most physicians were more concerned about breast cancer treatment than BCRL

treatment. However, as positive nurse-physician collaboration is increasingly important to quality patient outcomes [28], the participation of both groups of clinicians is necessary to adequately promote lymphedema self-management.

Data from this study revealed that some patients did not undertake self-management activities despite the recommendations provided by healthcare professionals, or they did not spend enough time per day on self-management activities. These observations are in line with those of a previous report [29]. Healthcare professionals should regularly evaluate if patients are performing lymphedema self-management activities and what activities are being performed through follow-up or during patient encounters. Modifications to self-management activities can only be performed if the resulting regimen is adequate for controlling the patient's lymphedema. While self-management regimens should be individualized, it is necessary to develop standardized lymphedema self-management regimens based on evidence-based nursing and to provide patients with scientific instructions.

Participants in this study identified a set of facilitators and barriers that affected lymphedema self-management, namely a sense of self-value, fear of aggravation, discomfort, restricted function, lack of time and energy, lack of skills and knowledge, insufficient family assistance, self-management effects, financial restraints, patient characteristics (age, education level, attitude, and self-discipline), and severity of the lymphedema. These findings were supported by previous reports [4, 12, 17, 29–31]. To some extent, there is an interaction between these factors and their role as facilitator or barrier is interchangeable [12]. For example, family assistance was regarded as a barrier in our study because patients largely received insufficient family support. However, family may become a potential facilitator of increased adherence to self-management if enough family assistance is provided to the patient. This suggests that health education for families to increase their awareness of the demands of lymphedema self-management is needed. There was a conflicting substantive relationship between self-management effects (barrier) and severity of the lymphedema (facilitator). A marked symptom improvement with self-care contributes to good adherence, but mild lymphedema symptoms were associated with poor attention to self-care. Therefore, healthcare professionals need to be aware of the relationships between facilitators and barriers, and are encouraged to take actions to strengthen the facilitators while controlling the barriers to improve adherence to self-management, such as for therapy-related factors, providing modified therapy measures may improve patient discomfort and function.

According to our results, most healthcare professionals described themselves as support providers, health educators, and supervisors. They also discussed the challenges they faced during their work. For the roles healthcare professionals played, most of them still played a traditional role that told

patients what to do [32]. In that case, patients tended to passively follow their instructions [16]. Literature shows that patients' self-efficacy is significantly associated with their adherence to self-management [33] and health beliefs about the controllability of illness [18]. These indicate providing motivation and encouragement to empower patients to increase their self-efficacy and beliefs is of great importance. It has been reported that self-management and patient-centered care are closely linked [34]. It is necessary for healthcare professionals to develop a relationship of trust and cooperation with patients. Moreover, various health education methods, such as Teach-Back Method [35] and avatar-based technology [36], can be utilized for the self-management training. Planned follow-up by WeChat, telephone, or email is needed to monitor patients. With regard to challenges healthcare professionals faced in the promotion of lymphedema self-management, greater effort is required for the administrators of hospitals to assign human resources rationally and optimize the self-management system.

Of note, some patients participating in our research expressed their emotional reactions towards lymphedema self-management, including anxiety, troublesome, hopelessness, and desire. The nature of time-consuming and the complexities of self-management regimens negatively affected their psychological health. With high distress patients suffered, they would like to be provided with psychological support. Besides psychological support, patients also had need for instrumental support and social support. Emotions can influence patients' self-efficacy to cope with challenging situations [16]. It has been demonstrated that psychological support and social support have positive impacts on individual's physical and psychological health [37]. Therefore, more attention should be paid to patients' emotional problems. Furthermore, peer support program has been found to have promising effects for BCRL patients [38], but healthcare professionals should be cautious when using the web-based group peer education without peer training, which may have adverse impacts on outcomes [39]. With regard to the problem of the availability and accessibility of medical resources, there is a need for government to provide patients with financial support to reduce their economic burden; for example, lymphedema therapy costs can be covered by health insurances. Moreover, literature shows that actively involving primary care physicians is beneficial to BCRL management [40], which may contribute to providing patients with universal and equitable access to lymphedema care. In that case, BCRL education and training for primary care providers are essential.

Limitations

This qualitative study was a monocentric study with small number of patients. The participants involved in the present

study were all female patients and there were fewer patients having severe lymphedema (stage 3) and subclinical lymphedema (stage 0); thus, the generalization of the findings and conclusions should be explained with caution. Further study is required to confirm these results. Future research should be conducted with diverse participants. Furthermore, studies that explore the perception of patient's family members are also recommended.

Conclusion

In conclusion, our study provides insights into the perspectives of BCRL patients and healthcare professionals on BCRL self-management, which is crucial to improve the promotion of lymphedema self-management and to enable patients to achieve a better quality of life. Our findings suggest that it is necessary to carry out more lymphedema educational programs to improve the level of knowledge and adaptive skills of both patients and healthcare professionals. A deeper understanding of the factors that influence compliance may contribute to providing targeted interventions and appropriate services. Better nurse-physician collaboration in the support of BCRL self-management is needed in the future and more holistic support should be provided to BCRL patients so as to enable them to properly adapt to their condition.

Acknowledgements The authors thank all the participants in this study for sharing their personal thoughts and experiences.

Code availability Not applicable

Author contribution Huihui Zhao and Chunlan Zhou designed the study; Huihui Zhao conducted the data collection/interviews; Huihui Zhao, Yanni Wu, and Chunlan Zhou qualitatively analyzed the data; Wenji Li, Xiaojin Li, and Liling Chen contributed to the analysis and interpretation of the interview data; Huihui Zhao drafted the manuscript and Yanni Wu helped draft the manuscript. All authors read and approved the final manuscript.

Funding This research was supported by the Natural Science Foundation of Guangdong Province of China (project no. 2020A1515010373).

Data availability Not applicable

Declarations

Ethics approval Ethical approval for this study was obtained from the ethical committees of the hospital.

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

Consent for publication Yes, according to Ethics approval.

Conflict of interest The authors declare no competing interests.

Disclaimer The funder had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

References

- Zhao H, Wu Y, Tao Y, Zhou C, De Vrieze T, Li X, Chen L (2020) Psychometric validation of the chinese version of the lymphedema functioning, disability, and health questionnaire for upper limb lymphedema in patients with breast cancer-related lymphedema. *Cancer Nurs Publish Ahead of Print*. <https://doi.org/10.1097/ncc.0000000000000848>
- Yildiz Kabak V, Gursen C, Aytar A, Akbayrak T, Duger T (2020) Physical activity level, exercise behavior, barriers, and preferences of patients with breast cancer-related lymphedema. *Support Care Cancer* 29:3593–3602. <https://doi.org/10.1007/s00520-020-05858-3>
- Rockson SG (2018) Lymphedema after breast cancer treatment. *N Engl J Med* 379(20):1937–1944. <https://doi.org/10.1056/NEJMcip1803290>
- Ostby PL, Armer JM, Smith K, Stewart BR (2018) Patient perceptions of barriers to self-management of breast cancer-related lymphedema. *West J Nurs Res* 40(12):1800–1817. <https://doi.org/10.1177/0193945917744351>
- Phillips GSA, Gore S, Ramsden A, Furniss D (2019) Lymphaticovenular anastomosis improves quality of life and limb volume in patients with secondary lymphedema after breast cancer treatment. *25 (5):859-864*. <https://doi.org/10.1111/tbj.13348>
- Eaton LH, Narkthong N, Hulett JM (2020) Psychosocial issues associated with breast cancer-related lymphedema: a literature review. *Curr Breast Cancer Rep*:1–9. <https://doi.org/10.1007/s12609-020-00376-x>
- Acebedo JC, Haas BK, Hermanns M (2021) Breast cancer-related lymphedema in hispanic women: a phenomenological study. *Journal of transcultural nursing : official journal of the Transcultural Nursing Society* 32(1):41–49. <https://doi.org/10.1177/1043659619891236>
- Burckhardt M, Belzner M, Berg A, Fleischer S (2014) Living with breast cancer-related lymphedema: a synthesis of qualitative research. *Oncol Nurs Forum* 41(4):E220–E237. <https://doi.org/10.1188/14.onf.e220-e237>
- Sun Y, Shigaki CL, Armer JM (2020) The influence of breast cancer related lymphedema on women's return-to-work. *Women Health (London, England)* 16:174550652090572. <https://doi.org/10.1177/1745506520905720>
- Arikan Dönmez A, Kuru Alici N (2020) Lived experiences for supportive care needs of women with breast cancer-related lymphedema: a phenomenological study. *1054773820958115*. doi: <https://doi.org/10.1177/1054773820958115>, 30, 1054773820958808
- Pervane Vural S, Ayhan FF, Soran A (2020) The role of patient awareness and knowledge in developing secondary lymphedema after breast and gynecologic cancer surgery. *Lymphat Res Biol* 18(6):526–533. <https://doi.org/10.1089/lrb.2020.0059>
- Jeffs E, Ream E, Shewbridge A, Cowan-Dickie S, Crawshaw D, Huit M, Wiseman T (2016) Exploring patient perception of success and benefit in self-management of breast cancer-related arm lymphoedema. *European journal of oncology nursing : the official journal of European Oncology Nursing Society* 20:173–183. <https://doi.org/10.1016/j.ejon.2015.08.001>
- Dunne S, Coffey L, Sharp L, Desmond D, Gooberman-Hill R, O'Sullivan E, Timmons A, Keogh I, Timon C, Gallagher P (2019) Integrating self-management into daily life following primary treatment: head and neck cancer survivors' perspectives. *J Cancer Surviv* 13(1):43–55. <https://doi.org/10.1007/s11764-018-0726-4>
- Budhwani S, Wodchis WP, Zimmermann C, Moineddin R, Howell D (2019) Self-management, self-management support needs and interventions in advanced cancer: a scoping review. *BMJ Support Palliat Care* 9(1):12–25. <https://doi.org/10.1136/bmjspcare-2018-001529>
- Radina ME, Armer JM, Stewart BR (2014) Making self-care a priority for women at risk of breast cancer-related lymphedema. *J Fam Nurs* 20(2):226–249. <https://doi.org/10.1177/1074840714520716>
- Been-Dahmen MJ, Grijpma JW, Ista E, Dwarswaard J, Maasdam L, Weimar W, Van Staa A, Massey EK (2018) Self-management challenges and support needs among kidney transplant recipients: a qualitative study. doi:<https://doi.org/10.1111/jan.13730>, 74, 2393, 2405
- Ostby PL, Armer JM (2015) Complexities of adherence and post-cancer lymphedema management. *J Personalized Med* 5(4):370–388. <https://doi.org/10.3390/jpm5040370>
- Alcorso J, Sherman KA, Koelmeyer L, Mackie H, Boyages J (2016) Psychosocial factors associated with adherence for self-management behaviors in women with breast cancer-related lymphedema. *Support Care Cancer* 24(1):139–146. <https://doi.org/10.1007/s00520-015-2766-x>
- Ridner SH, Rhoten BA, Radina ME, Adair M, Bush-Foster S, Sinclair V (2016) Breast cancer survivors' perspectives of critical lymphedema self-care support needs. *Support Care Cancer* 24(6):2743–2750. <https://doi.org/10.1007/s00520-016-3089-2>
- Temur K, Kapucu S (2019) The effectiveness of lymphedema self-management in the prevention of breast cancer-related lymphedema and quality of life: a randomized controlled trial. *European journal of oncology nursing : the official journal of European Oncology Nursing Society* 40:22–35. <https://doi.org/10.1016/j.ejon.2019.02.006>
- van Het Bolscher-Niehuis MJT, Uitdehaag MJ, Francke AL (2020) Community nurses' self-management support in older adults: a qualitative study on views, dilemmas and strategies. *Health & social care in the community* 28(1):195–203. <https://doi.org/10.1111/hsc.12853>
- Creswell JW (2012) *Research design : qualitative, quantitative, and mixed methods approaches* 4th ed.
- Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care : journal of the International Society for Quality in Health Care* 19(6):349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Saunders B, Sim J (2018) Saturation in qualitative research: exploring its conceptualization and operationalization. . doi:<https://doi.org/10.1007/s11135-017-0574-8>, 52, 1893, 1907
- Castleberry A, Nolen A (2018) Thematic analysis of qualitative research data: is it as easy as it sounds? *Currents in pharmacy teaching & learning* 10(6):807–815. <https://doi.org/10.1016/j.cptl.2018.03.019>
- Tam EK, Shen L, Munneke JR, Ackerson LM, Partee PN, Somkin CP, André M, Kutner SE, Thiadens SR, Kwan ML (2012) Clinician awareness and knowledge of breast cancer-related lymphedema in a large, integrated health care delivery setting. *Breast Cancer Res Treat* 131(3):1029–1038. <https://doi.org/10.1007/s10549-011-1829-z>
- Abu Sharour L (2019) Oncology nurses' knowledge about lymphedema assessment, prevention, and management among women

- with breast cancer. *Breast Dis* 38(3-4):103–108. <https://doi.org/10.3233/bd-190381>
28. House S, Havens D (2017) Nurses' and physicians' perceptions of nurse-physician collaboration: a systematic review. *J Nursing Admin* 47(3):165–171. <https://doi.org/10.1097/naa.0000000000000460>
 29. Ridner SH, Dietrich MS, Kidd N (2011) Breast cancer treatment-related lymphedema self-care: education, practices, symptoms, and quality of life. *Support Care Cancer* 19(5):631–637. <https://doi.org/10.1007/s00520-010-0870-5>
 30. Fu MR (2005) Breast cancer survivors' intentions of managing lymphedema. *Cancer Nurs* 28(6):446–457; quiz 458–449. <https://doi.org/10.1097/00002820-200511000-00007>
 31. Jin J, Sklar GE, Min Sen Oh V, Chuen Li S (2008) Factors affecting therapeutic compliance: a review from the patient's perspective. *Ther Clin Risk Manag* 4(1):269–286. <https://doi.org/10.2147/tcrm.s1458>
 32. Been-Dahmen JM, Dwarswaard J, Hazes JM, van Staa A, Ista E (2015) Nurses' views on patient self-management: a qualitative study. *J Adv Nurs* 71(12):2834–2845. <https://doi.org/10.1111/jan.12767>
 33. Brown JC, Cheville AL, Tchou JC, Harris SR, Schmitz KH (2014) Prescription and adherence to lymphedema self-care modalities among women with breast cancer-related lymphedema. *Support Care Cancer* 22(1):135–143. <https://doi.org/10.1007/s00520-013-1962-9>
 34. Killingback C, Thompson MA, Chipperfield S (2020) Transitions from healthcare to self-care: a qualitative study of falls service practitioners' views on self-management. doi:<https://doi.org/10.1080/09638288.2020.1849423>, 1, 8
 35. Ha Dinh TT, Bonner A, Clark R, Ramsbotham J, Hines S (2016) The effectiveness of the teach-back method on adherence and self-management in health education for people with chronic disease: a systematic review. *JBI Database System Rev Implement Rep* 14(1): 210–247. <https://doi.org/10.11124/jbisrir-2016-2296>
 36. Wonggom P, Kourbelis C, Newman P, Du H, Clark RA (2019) Effectiveness of avatar-based technology in patient education for improving chronic disease knowledge and self-care behavior: a systematic review. *JBI Database System Rev Implement Rep* 17(6):1101–1129. <https://doi.org/10.11124/jbisrir-2017-003905>
 37. Wei D, Liu XY, Chen YY, Zhou X, Hu HP (2016) Effectiveness of physical, psychological, social, and spiritual intervention in breast cancer survivors: an integrative review. *Asia Pac J Oncol Nurs* 3(3): 226–232. <https://doi.org/10.4103/2347-5625.189813>
 38. Anderson EA, Armer JM (2021) Factors impacting management of breast cancer-related lymphedema (BCRL) in Hispanic/Latina breast cancer survivors: a literature review. *Hispanic health care international : the official journal of the National Association of Hispanic Nurses* doi:<https://doi.org/10.1177/1540415321990621>, 154041532199062
 39. Hu J, Wang X, Guo S, Chen F, Wu YY, Ji FJ, Fang X (2019) Peer support interventions for breast cancer patients: a systematic review. *Breast Cancer Res Treat* 174(2):325–341. <https://doi.org/10.1007/s10549-018-5033-2>
 40. Mete Civelek G, Aypak C, Turedi O (2016) Knowledge of primary care physicians about breast-cancer-related lymphedema: Turkish perspective. *J Cancer Educ Official J Am Assoc Cancer Educ* 31(4): 687–692. <https://doi.org/10.1007/s13187-015-0880-6>

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.