1

# **Breast Cancer-Related Lymphedema Self-Care Practices: A Cross-Sectional Descriptive Study**

Berna DİZER<sup>1</sup>, Şule OLGUN<sup>2</sup>, Ayvaz Ulaş URGANCI<sup>1</sup>

<sup>1</sup>Department of Operation Room Services, İzmir Tınaztepe University Vocational School of Health Services, İzmir, Türkiye

Cite this article as: Dizer B, Olgun S, Urgancı AU. Breast cancer-related lymphedema self-care practices: A cross-sectional descriptive study. Arch Health Sci Res. 2025, 12, 0165, doi: 10.5152/ArcHealthSciRes.2025.24165

# What is already known on this topic?

- Breast cancer-related lymphoedema (BCRL) can affect not only the physical health but also the emotional well-being of patients.
- With lymphoedema, self-care practices (such as protecting the affected area and effectively managing the condition) are crucial for prevention and treatment.
- However, research shows that many patients struggle with a lack of education and have difficulty adhering to recommended self-care routines, which can lead to poor health outcomes.

# What does this study add on this topic?

- · This study assesses self-care practices among BCRL patients, emphasizing protective behaviors, activity management, pressure management, and sustainability.
- Sociodemographic and clinical factors that influence self-care practices include age, marital status, and presence of chronic disease.
- The findings emphasize the need for targeted educational interventions and support mechanisms to improve self-care compliance.

#### **ABSTRACT**

**Objective:** Lymphedema is a condition seen in breast cancer patients after mastectomy and significantly affects the quality of life. Self-management strategies are important for preventing lymphedema and reducing its severity. This study aims to evaluate the self-care abilities of breast cancer-related lymphedema (BCRL) patients after surgery.

Methods: This study was conducted in a cross-sectional descriptive design. Study data were obtained from a single private hospital between August 2021 and May 2022. The study sample consisted of 53 patients who had undergone mastectomy in the last 2 years and were at risk of developing lymphedema. A socio-demographic data form and the Breast Cancer Related Lymphedema Self-Care Scale were used to collect data. The relationship between sociodemographic and clinical variables and the Breast Cancer Related Lymphedema Self-Care Scale was evaluated with Pearson and Spearman correlation tests.

**Results:** The mean score of the BCRL Self-Care Scale was  $70.79 \pm 13.49$ . 79.2% of patients reported consistently adhering to infection prevention measures, 37.7% performed recommended exercises regularly, and 56.6% did not wear compression garments daily. Younger patients showed better adherence to self-care in the Activity subscale (P < .05), and married individuals had higher Sustainability subscale scores. Chronic disease was associated with lower protection scores (P < .001).

Conclusion: Sociodemographic and clinical factors such as knowledge, marital status, and chronic illness significantly influence self-care practices. While infection prevention was strong, exercise and compression garment use were insufficient. Interventions focused on physical activity and pressure management are needed to improve lymphedema outcomes.

Keywords: Breast neoplasms, lymphedema, mastectomy, patients, self care

## Introduction

Breast cancer is the leading cause of cancer in women worldwide, accounting for 11.7% of all cancer cases. Advances in surgical treatment, chemotherapy, radiotherapy, and targeted therapies have significantly improved survival rates for breast cancer, with 90% of patients surviving more than 5 years post treatment. However, patients often experience various degrees of complications, including breast cancer-related lymphedema (BCRL).<sup>2</sup> Previous studies have reported that the risk of developing secondary lymphedema following breast cancer treatment ranges from 14% to 60%.3 This wide variation in risk

Received: November 7, 2024

Revision Requested: December 28, 2024 Last Revision Received: December 28, 2024

Accepted: February 7, 2025 Publication Date: May 12, 2025



<sup>&</sup>lt;sup>2</sup>Department of Operation Room Services, İzmir Kavram Vocational School of Health Services, İzmir, Türkiye

emphasizes the importance of early detection and effective management strategies to reduce the long-term impact of BCRL on survivors' quality of life.

Breast cancer remains the most prevalent form of cancer globally and is the leading cause of death among women, including in Türkiye. According to the World Health Organization's (WHO) International Agency for Research on Cancer (IARC) 2018 data, there were 2000 088 new cases of breast cancer worldwide, only slightly fewer than lung cancer, the most common type of cancer. In Türkiye, the prevalence of breast cancer exceeds 50 per 100 000, with 22 500 newly diagnosed cases in 2018 and a prevalence rate of 45.6 per 100 000.4

While surgical procedures for breast cancer, along with postoperative chemotherapy and radiotherapy, significantly prolong patient survival, they also negatively impact quality of life, leading to longterm treatment-related complications.<sup>5</sup> Common post-treatment complications include shoulder dysfunction, upper extremity muscle weakness, and lymphedema. Lymphedema occurs due to the accumulation of protein-rich fluid in the interstitial space, resulting from disruption, damage, or dysfunction of the lymphatic system in the treated limb. Despite its frequency, lymphedema is one of the least understood and under-researched complications of cancer and its treatment. Lymphedema typically develops within the first 18 months post-treatment, although it can manifest at any point in a patient's life. As a chronic condition, lymphedema introduces both physical and psychosocial challenges, significantly diminishing patients' quality of life. Like cancer, early diagnosis and timely treatment of lymphedema are critical.

Lymphedema affects between 8% and 56% of breast cancer patients post-treatment, and if left untreated, its chronic and progressive nature increases the risk of infections. However, if detected early, lymphedema can be managed effectively, particularly in its initial stages, making early intervention essential. For clinicians, lymphedema represents a crucial postoperative complication due to its frequency and its profound impact on patient function and quality of life. <sup>6,7</sup> Additionally, literature indicates that most women are unaware of lymphedema before its onset and often fail to recognize its symptoms. <sup>5</sup>

Axillary lymph nodes play a crucial role in the immune and circulatory systems, with 35-40 nodes on average located in the axillary region.<sup>8</sup> In breast cancer surgeries, lymph nodes may be preserved or removed depending on the surgery type. Removal of lymph nodes, particularly in radical and modified radical mastectomy, increases the risk of developing lymphedema in the postoperative period.

Patients with BCRL experience a range of physical symptoms such as pain, swelling, numbness, heaviness, and movement restrictions, as well as psychological issues like depression and body image distress. Additionally, BCRL impacts daily living (e.g., personal limitations), social interactions (e.g., social withdrawal), finances (e.g., treatment costs), and work performance (e.g., return to work). These challenges can negatively affect their ability to fulfill roles within the family and society.<sup>9</sup>

Preventive strategies, such as maintaining an ideal body weight, engaging in regular physical exercise, and protecting the affected limb from trauma, are essential. Compression garments, prescribed by physicians, are also critical in managing the condition. Despite the recognized importance of self-management in BCRL, only 71% of patients report engaging in self-care behaviors, and only 19.5% adhere to all recommended practices. Factors such as lack of knowledge, disease severity, and limited resources impact self-management behaviors.

Given the significant impact of lymphedema on patients' quality of life and the role of self-care in its prevention and management, it is essential to educate women both before and after breast cancer surgery. However, many patients report receiving inadequate information about lymphedema management. Therefore, this study aims to assess the self-care abilities of patients with BCRL following breast surgery.

#### **Research Ouestions**

- What are the self-care abilities of patients with BCRL following breast surgery?
- 2. Which socio-demographic and clinical factors influence these selfcare abilities?

## **Material and Method**

## **Study Design**

This study was conducted as a cross-sectional descriptive study, with data collected between August 2021 and May 2022. Ethical approval was obtained from the Beykent University Scientific Research and Publication Ethics Committee (Approval Number: 2021/2710, Date: July 02, 2021), and informed consent was taken from all participants. The study was carried out at a private hospital, including patients who had undergone mastectomy and were at risk of developing lymphedema. Inclusion criteria included patients aged 18 years and older who had undergone mastectomy within the past 2 years and were able to provide informed consent. Exclusion criteria included patients with other severe chronic diseases or those experiencing postoperative complications. The sample size was calculated using G\*Power 3.1 software. An a priori power analysis was conducted with a power  $(1-\beta)$  of 0.80, an effect size (Cohen's d) of 0.5, and a significance level ( $\alpha$ ) of 0.05. Based on this analysis, a minimum of 53 participants was determined to be sufficient to detect significant differences with a 95% CI. The study was reported using the STROBE checklist.<sup>12</sup>

## **Data Collection Procedure**

Data were collected through face-to-face interviews during the patients' follow-up appointments by all researchers, especially by the doctor who performed the surgery. Data collectors adhered to the research protocol and followed standardized procedures to ensure consistency in the data collection process. The study was conducted in a private hospital specializing in oncology care. Participants were first administered a 16-question socio-demographic questionnaire, followed by the BCRL Self-Care Scale. Data confidentiality was ensured by assigning unique identification codes to each participant and securely storing all data in password-protected digital files accessible only by the research team. All participants voluntarily participated in the study, and written informed consent was obtained before inclusion.

# Socio-Demographic Data Form

The socio-demographic data form was developed by the researcher based on the literature. 1.2.3.5.7.8 The form consists of 16 questions: the first 7 questions assess participants' age, gender, marital status, education level, place of residence, economic status, and household composition. The remaining 9 questions address the presence of a first-degree relative with breast cancer, the presence of a chronic disease, and whether the participant had received information on preventing lymphedema after mastectomy.

# **Breast Cancer Related Lymphedema Self-Care Scale**

The BCRL Self-Care Scale, developed by Deveci et al<sup>11</sup> in 2019, was used to assess self-care practices in women who developed lymphedema following breast cancer treatment. The scale consists of 31 questions across 4 sub-dimensions: protection, activity and disease process management, pressure management, and sustainability. It is a 4-point Likert scale, where responses are scored as follows: 1 = Never, 2 = Sometimes,

3=Often, 4=Always. Total scores are calculated by summing all item responses, with possible scores ranging from 31 to 124. Higher scores indicate better self-care practices. Items 4, 5, 6, 8, 9, 10, 11, 20, 21, 22, and 28 are reverse-scored, meaning that for these items, 1 becomes 4, 2 becomes 3, and so on. For this study, the Cronbach's  $\alpha$  was found to be 0.85, demonstrating good internal consistency.

## **Data Analysis**

Data were analyzed using SPSS (Statistical Package for Social Sciences). Descriptive statistics (frequency, percentage, mean) and analysis of variance (ANOVA) were used for data evaluation. Post-hoc tests (Tukey's HSD) were applied to assess significant differences between groups where ANOVA results were significant. Correlation coefficients were calculated using Pearson correlation for continuous variables and Spearman correlation for categorical and ordinal variables. A *P*-value of less than .05 was considered statistically significant.

#### Results

The study included 53 participants, with 49.1% aged 45-54 years and 18.9% aged 35-44 years. The mean age was  $46.95 \pm 9.27$  years. Most participants (77.4%) were married, and 45.3% had completed primary education. In terms of economic status, 66.0% reported that their income matched their expenses, and 88.7% lived with their spouse and children

Regarding health, 37.7% of participants had a chronic illness, and 28.3% reported a family history of breast cancer. Among these relatives, 88.7% were still alive. Concerning lymphedema awareness, 69.8% had received information about it, primarily from doctors (50.9%). However, 50.9% found this information insufficient (Table 1).

As presented in Table 2, in the Protection sub-dimension, 79.2% of patients reported always protecting their arm from infections, such as avoiding animal bites or injuries during manicures. However, only 35.2% of participants consistently wore gloves while doing household or garden work. In the Activity and Disease Process Management sub-dimension, 37.7% of participants indicated that they always performed the recommended exercises, while 34.0% reported performing lymphatic massage occasionally when they experienced lymphedema.

In the Pressure Management sub-dimension, 50.9% of participants were unaware of how to properly care for or maintain their compression sleeves, and 49.1% did not wear compression sleeves during exercise. In the Sustainability sub-dimension, 52.8% of patients actively sought out information to improve their self-care practices, and 54.7% reported that lymphedema self-care did not feel burdensome. However, 35.8% of participants admitted to postponing self-care activities despite knowing their benefits.

Table 3 presents the effects of sociodemographic variables on overall lymphedema self-care and its sub-dimensions. Age showed a significant difference in the Activity sub-dimension (P=.023), with younger patients scoring higher in this area. However, age did not significantly affect the overall self-care score or other sub-dimensions. Marital status showed a significant difference in the Sustainability sub-dimension (P<<.001), where married individuals scored higher in maintaining long-term self-care practices.

The chronic disease variable showed a significant difference in the Protection sub-dimension (P=.002), with patients having chronic diseases scoring lower in protective behaviors. However, chronic disease did not significantly impact the overall self-care score. Knowledge competence was significantly associated with better overall self-care practices (P=.014), with more knowledgeable patients reporting higher self-care scores.

Table 1. Socio-Demographic Characteristics of Studi Variable	n	%
Age Group		70
25-34	7	13.2
35-44	10	18.9
45-54	26	49.1
55-65	10	18.9
Marital Status	10	10.9
Married	41	77.4
Single	12	77.4 22.6
Education Level	12	22.0
		45.2
Primary education	24	45.3
High school	12	22.6
University	17	32.1
Place of Residence		
Province	31	58.5
District	22	37.7
Economic Status		
Income less than expenses	7	13.2
Income equal to expenses	35	66.0
Income more Than expenses	11	20.8
Living Status		
Alone	4	7.5
With spouse and children	47	88.7
With family elders	2	3.8
Chronic Disease Status		
Yes	20	37.7
No	33	62.3
Family History of Breast Cancer		
Yes	15	28.3
No	38	71.7
Survival Status of Relatives with Breast Cancer		
Alive	47	88.7
Deceased	6	11.3
Received Information About Lymphedema		
Yes	37	69.8
No	16	30.2
Source of Information About Lymphedema		
Doctors	27	50.9
Nurses/Other health personnel	10	18.9
No one	16	30.2
Adequacy of Information		
Sufficient	10	18.9
Insufficient	27	50.9
No Information	16	30.2

The family history of breast cancer did not show any statistically significant correlation with the overall self-care score or any sub-dimensions. The adequacy of information variable showed weak, non-significant trends across all dimensions, indicating no significant effect on self-care behaviors. Additionally, variables such as education level, place of residence, economic status, and receipt of lymphedema information did not show statistically significant differences in either the overall self-care score or any sub-dimensions.

Table 4 presents the correlations between sociodemographic and clinical variables and self-care scores in lymphedema patients. A weak negative correlation was found between age and self-care score (r = -0.235), indicating that as age increases, self-care practices tend to

Sustainability

Sub-Dimension and Scale Question	Always (%)	Often (%)	Sometimes (%)	Never (%)
Protection				
wear gloves when doing household or garden work	35.2	5.6	42.6	16.6
protect my arm from extreme heat and cold	52.8	22.6	17.0	7.5
protect my arm from infections (e.g., animal bites, manicures)	79.2	7.5	5.7	7.5
lift weights with my affected arm	7.5	5.7	35.8	50.9
take blood pressure using my affected arm	3.8	7.5	7.5	81.1
have blood drawn or injections from my affected arm	9.4	7.5	5.7	77.4
observe my affected arm for signs of infection (e.g., redness, swelling)	67.9	7.5	7.5	17.0
do household chores requiring repetitive motion (e.g., window washing)	17.0	5.7	43.4	34.0
lie on my affected arm at night	9.4	15.1	39.6	35.8
wear clothes that squeeze my affected arm	11.3	9.4	24.5	54.7
wear jewelry (e.g., rings, bracelets) on my affected arm	9.4	1.9	28.3	60.4
Activity and Disease Process Management				
raise my affected arm periodically during the day	18.9	34.0	32.1	15.1
do the exercises recommended to me	37.7	22.6	22.6	17.0
perform lymphatic massage when I have lymphedema	17.0	18.9	34.0	30.2
apply moisturizer to my affected arm	11.3	30.2	28.3	30.2
measure my arm at home	3.8	20.8	34.0	41.5
go for lymphedema check-ups as often as recommended	24.5	18.9	15.1	41.5
Pressure Management				
wear my compression sleeve while exercising	20.8	13.2	17.0	49.1
wear my compression sleeve or apply my bandage every day	9.4	11.3	22.6	56.6

30.2

11.3

24.5

20.8

37.7

22.6

37.7

34.0

54.7

17.0

52.8

35.8

7.5

17.0

15.1

24.5

13.2

13.2

11.3

13.2

13.2

3.8

13.2

22.6

decline slightly. Marital status showed a very weak positive correlation with self-care (r=0.065), though this relationship was not statistically significant. Education level demonstrated a weak positive correlation with self-care score (r=0.199), suggesting that individuals with higher educational attainment tend to engage in better self-care behaviors.

I know how to wash or maintain my compression sleeve

When my family asks me to do something, I prioritize their work first

I carry antibiotic ointment in my bag in case I get cuts on my affected arm

I know what to do if I develop redness, swelling, or increased temperature

I know what I need to do to prevent the progression of lymphedema

I can usually find effective solutions for my problems with lymphedema

I put off doing things that I know will be useful for my self-care

I only do self-care practices when household chores are finished

I postpone self-care practices when I am sick

I can maintain my self-care while working

Lymphedema self-care is not a burden for me

I try to be informed to improve my self-care

Economic status was weakly positively correlated with self-care (r=0.146), with wealthier individuals showing slightly better self-care practices. The presence of a chronic disease had a modest positive correlation with self-care (r=0.226), indicating that patients managing chronic conditions engage in more self-care activities.

11.3

28.3

43.4

32.1

20.8

17.0

11.3

28.3

20.8

35.8

24.5

17.0

50.9

43.3

17.0

22.6

28.3

47.2

39.6

24.5

11.3

43.4

9.4

24.5

educational attainment tend to engage in better self-care behaviors. managir

Table 3. Lymphedema Self-Care Scale: General and Sub-Dimensions by Sociodemographic Variables						
Variable	General Self-Care (P)	Protection (P)	Activity (P)	Pressure (P)	Sustainability (P)	
Age	0.523	.999	.023*	.712	.582	
Marital status	0.435	.101	.401	.958	<.001**	
Education level	0.880	.678	.291	.291	.322	
Place of residence	0.862	.163	.672	.541	.405	
Economic status	0.265	.826	.543	.485	.231	
Chronic disease	0.666	.002**	.434	.630	.882	
Lymphedema information	0.100	.827	.119	.367	.755	
Knowledge competence	0.014**	Not tested	Not tested	Not tested	Not tested	
Family history of breast	0.276	.325	.429	.503	.371	
Adequacy of information	0.138	.194	.327	.284	.443	

For comparison of categorical variables like marital status, place of residence, and chronic disease: t-test was used.

For comparison of multiple groups like age and education level: ANOVA (Analysis of Variance) was applied.

Bold values are used specifically to emphasise statistically significant p-values. These are shown as p < 0.05 and p < 0.001 to indicate significance levels in accordance with standard reporting practices.

<sup>\*</sup> p<0,05 \*\* p<0,001

Table 4. Correlation of Sociodemographic and Clinical Variables with Self-Care Scores in Lymphedema Patients

Sen care scores in Lympheaema rations			
Variable	r*		
Age	-0.235		
Marital status	0.065		
Education level	0.199		
Economic status	0.146		
Presence of chronic disease	0.226		
Lymphedema knowledge vs. Self-care score	0.177		
Family history of breast	0.207		
Information about lymphedema	-0.039**		
Adequacy of information	-0.104		

<sup>\*</sup> *r* indicates the correlation coefficient with the Self-care score. Pearson correlation was used for continuous variables, and Spearman correlation was used for categorical and ordinal variables.

Bold values are used specifically to emphasise statistically significant p-values. These are shown as p < 0.05 and p < 0.001 to indicate significance levels in accordance with standard reporting practices.

A weak positive correlation was observed between lymphedema knowledge and self-care scores (r = 0.177), suggesting that greater knowledge of lymphedema may be associated with improved self-care practices.

Additionally, a weak positive correlation was found between having a family history of breast cancer and self-care score (r=0.207). In contrast, the correlations between receiving information about lymphedema and self-care score (r=-0.039), as well as the adequacy of information (r=-0.104), were weakly negative, indicating that these variables do not significantly impact self-care behaviors.

This figure shows the average scores for the BRCL Self-Care Scale sub-dimensions: Protection, Activity and Disease Management, Pressure Management, and Sustainability. Error bars represent the standard deviation for each sub-dimension. The Protection sub-dimension has an average score of 13.46  $\pm$  3.86, Activity and Disease Management 21.47  $\pm$  5.00, Pressure Management 17.45  $\pm$  3.52, and Sustainability 17.08  $\pm$  5.29 (Figure 1).

# Discussion

Breast cancer patients encounter various challenges when managing lymphedema on their own. Therefore, it is crucial to identify potential facilitators and barriers to provide practical recommendations that promote self-management activities for lymphedema. In this study, the knowledge levels regarding lymphedema among patients who underwent breast surgery were examined, as well as the influence of various sociodemographic and clinical factors on their self-care behaviors. The analysis assessed the impact of variables such as age. marital status, chronic disease status, and lymphedema knowledge competence on self-care practices. The findings revealed that younger patients scored higher in the activity domain, while married individuals demonstrated greater success in maintaining long-term self-care practices. Additionally, patients with chronic diseases were found to score lower in protective behaviors, suggesting a negative impact of chronic illness on self-care. Lymphedema knowledge competence was positively correlated with overall self-care, indicating that patients with higher levels of knowledge exhibited better self-care practices.

In this study, the average total score for patients' self-care on the Lymphedema Self-Care Scale was calculated as 70.79 out of 124, indicating that self-care practices among patients are at 57.09% on average (Figure 1). This moderate level of self-care performance suggests that while patients are somewhat managing their condition, there is significant room for improvement. Compared to other studies, this finding aligns with the work of Alcorso et al (2016), who reported that while 71% of patients engage in self-management behaviors, only 19.5% fully adhere to recommended practices. The discrepancy between awareness of self-care importance and actual adherence may be attributed to psychosocial factors, such as emotional and social support, which Alcorso et al 13 identified as key determinants of patient engagement.

In this study, none of the participants reached the maximum self-care score, with the highest being 104. This finding is consistent with the study by Zhao et al (2021),9 which highlighted that both patients and healthcare professionals often acknowledge the importance of self-care but struggle with limited knowledge and tailored interventions.

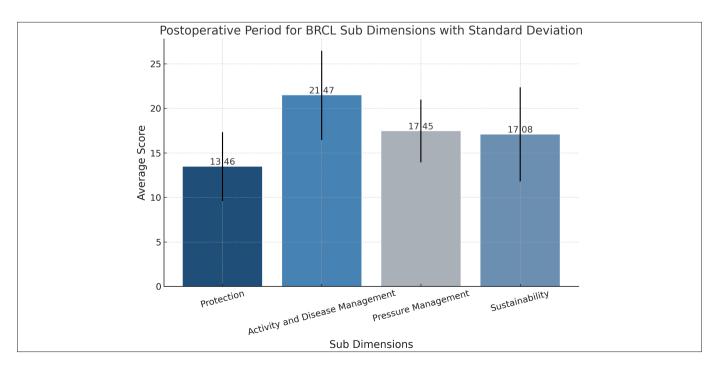


Figure 1. Breast Cancer Related Lymphedema Self-Care Subscales and Mean Values.

Zhao's research suggests that the gap between understanding and implementation may stem from insufficient education and inadequate resources.<sup>9</sup> Similarly, the variation in our participants' scores (ranging from 42 to 104) reflects the broader issue of unequal access to information and support, which has been highlighted in the literature as a barrier to effective self-management.

Temür and Kapucu (2018)<sup>14</sup> emphasized the importance of self-managed lymphedema care to improve patients' quality of life. In their study, although they defined lymphedema as a chronic and complex condition, they underlined that effective self-management, including regular monitoring and preventive measures, can significantly reduce the incidence of lymphedema and improve the quality of life. Similarly, a systematic review by Perdomo et al (2022)<sup>15</sup> found that educational interventions provided at various stages of breast cancer treatment are critical for better adherence to self-care and the prevention of lymphedema complications. These studies are in line with the findings, suggesting that inadequate education and healthcare resource limitations need to be addressed to improve self-care outcomes. <sup>14,15</sup> The findings and the literature advocate for increased educational efforts and tailored interventions to enable patients to effectively manage lymphedema.

In this study, the majority of patients were middle-aged and predominantly married, which aligns with the findings of Kuruvilla et al (2022), 16 who reported that the average age of 65 543 postmastectomy breast cancer patients was middle-aged (mean age 59 ± 20 years). These findings suggest that the demographics of this study are comparable. The high proportion of married individuals highlights the potential role of family support in lymphedema management, as spousal or family involvement can significantly aid in adherence to self-care practices. Fu<sup>17</sup> conducted a qualitative study and found that single women expressed difficulties in balancing lymphedema self-care with household tasks, emphasizing the importance of external support systems. This suggests that family support, particularly for married individuals, may contribute to more effective lymphedema management by alleviating some of the burdens associated with daily self-care and household responsibilities. Therefore, integrating family education into lymphedema care plans could be crucial for improving outcomes, especially for married patients who may rely on spousal assistance.

In addition to the findings of this study, other research has consistently emphasized the beneficial impact of spousal and family support in managing BCRL and other chronic conditions. Family and friends play a critical role in helping affected individuals cope with lymphedema, particularly by providing emotional and practical assistance. Acebedo et al (2021)<sup>18</sup> highlighted with BCRL received crucial support from family members, which significantly improved their ability to manage the condition. Similarly, Arikan Dönmez et al (2021)<sup>19</sup> found that women with BCRL expressed the need for supportive care, with family and friends being key to fulfilling those needs. Ostby et al (2018)<sup>20</sup> also explored patient perceptions of barriers to self-management, revealing that those with strong family support reported fewer challenges in adhering to self-care practices. These studies underscore the importance of involving family members in the management plan for BCRL patients, as their support can mitigate the emotional and physical demands of managing a chronic condition like lymphedema, leading to better adherence and improved outcomes.

The literature indicates that mastectomy patients who are informed about lymphedema preoperatively have a lower likelihood of developing lymphedema postoperatively, and they tend to experience lymphedema symptoms later. This delay is attributed to postoperative anti-lymphedema exercises.<sup>21</sup> In this study, 69.8% of patients reported receiving information about lymphedema, but 50.9% received this

information from doctors, and 50.9% found the information inadequate. Similarly, Lee et al<sup>22</sup> found that 82.5% of breast cancer patients who developed lymphedema were unaware of lymphedema risk factors, with 40.9% receiving information from nurses and 38% from doctors. Likewise, Thomas-Mac Lean et al<sup>23</sup> found that patients who developed lymphedema were uninformed about the condition before its onset and, therefore, unable to recognize the symptoms. Paskett and Stark<sup>24</sup> also showed that 90% of patients who developed lymphedema had no prior knowledge of preventive behaviors.<sup>22,23,24</sup>

The findings of thisr study, alongside the existing literature, underscore the critical need to improve the quality of information provided to patients regarding lymphedema, particularly for those undergoing breast surgery. The results align with those of Douglass et al (2016), 25 who demonstrated the crucial role of early education in preventing lymphedema and highlighted the positive effects of education on managing risk factors. Similarly, Wang et al (2024)<sup>26</sup> conducted a meta-synthesis that identified knowledge gaps as a significant barrier to effective self-management in patients with BCRL, which mirrors the issues found in the study. Although many patients in the research reported receiving information about lymphedema, the perception of this knowledge as inadequate was striking. This finding is consistent with the qualitative research by Chen et al (2023)27, which reported that patients experienced difficulties with post-surgical self-care due to limited education. These consistent findings across studies highlight the need for healthcare professionals to play a more proactive role in providing comprehensive preoperative and postoperative education on lymphedema risk factors. Enhancing access to clear, detailed information can empower patients to perform self-care more effectively and potentially prevent the onset or complications of lymphedema. Therefore, the results of this study are that better educational practices are necessary to improve the management of this chronic condition.

In the protection subscale of the lymphedema self-care scale, 79.2% of patients always practiced basic protective behaviors, such as protection from infections, while only 35.2% stated that they used gloves when doing housework or gardening. These findings are consistent with the study by Zhao et al (2021).9 Zhao's study showed that patients were more successful in infection prevention behaviors, but there were deficiencies in other protective measures. In addition, in this study, the presence of chronic disease was found to negatively affect protective behaviors. Patients with chronic diseases exhibit lower protective behaviors due to the additional burden of their diseases. The literature also supports these findings; it is stated that protective behaviors are related to the general health status and social support of patients.

In the activity and disease process management subscale, 37.7% of participants reported that they always did the recommended exercises, but only 17% reported practicing lymphatic massage. The study by Alcorso et al (2016)<sup>13</sup> emphasized the importance of self-care practices in lymphedema management but showed that patients had difficulties in implementing all recommended behaviors. In this study, it was observed that the age factor was important in this subscale; younger patients were found to be more successful in activity management. This difference may be explained by the fact that younger individuals have more knowledge and can integrate this knowledge into their daily lives more effectively.

In the pressure management subscale, 50.9% of the participants stated that they did not know how to use or maintain compression garments. This finding is consistent with the literature showing that pressure applications play a critical role in the management of lymphedema.<sup>25</sup> However, in the study, it was found that patients with a higher education level were more successful in this subdimension. It has been evaluated and understood that patients with a higher level of education

have better knowledge about the use of compression garments and are better able to apply this knowledge.

This positive effect of education level on pressure management is similarly emphasized in the literature. In the sustainability subscale, 52.8% of the patients stated that they sought information to improve their self-care practices, but 35.8% stated that they postponed self-care practices that they knew were useful. Fu<sup>17</sup> showed that single women had difficulty balancing lymphedema self-care with daily life responsibilities and postponed self-care practices more frequently. Similarly, marital status emerged as an important factor in the study; married individuals were found to be more successful in sustainable self-care practices thanks to the support they received from their spouses.

In particular, it is believed that family support can alleviate the burden of self-care and provide more regular and effective management. These results provide important clues for the development of individualized approaches in the management of lymphedema. Particularly, early education on lymphedema and programs supporting self-care play a significant role in preventing complications. Donahue et al (2023)<sup>28</sup> emphasized the importance of patient education strategies in the prevention and treatment of lymphedema after breast cancer. It has been noted that educational programs play a critical role in raising awareness of lymphedema and enhancing patient adherence to self-care practices.

#### Limitations

The sample was limited to one private hospital, which may reduce the generalizability of the results. Future studies with larger and more diverse samples are recommended.

## Conclusion

This study assessed BCRL self-care practices, finding that while patients took regular steps to prevent infections, they were insufficient in areas such as exercise, lymphatic massage, and pressure garment use, with particularly low adherence to daily pressure garment use. Despite many patients not finding self-care challenging, family responsibilities often took priority over self-care, leading to difficulties in sustainability and pressure management. To address these gaps, it is crucial to strengthen patient education on lymphedema risk factors and self-care practices, particularly focusing on the use of compression garments, recognizing infection signs, and performing lymphatic massage. Continuous monitoring by healthcare professionals and support through certification programs are essential. Technological solutions like mobile apps and online systems can further help monitor and support self-care practices.

**Data Availability Statement:** The data that support the findings of this study are available on request from the corresponding author.

**Ethics Committee Approval:** Written permission was obtained from the Beykent University Scientific Research and Publication Ethics Committee (Approval number: 2021/2710, Date: July 02, 2021) and the Medical Director of Tinaztepe Hospital.

**Informed Consent:** Written informed consent forms were obtained from all patients.

Peer-review: Externally peer-reviewed.

**Author Contributions:** Concept – B.D., S.O.; Design – B.D., S.O., A.U.U.; Supervision – S.O., A.U.U.; Resources – B.D.; Materials – B.D.; Data Collection and/or Processing – B.D.; Analysis and/or Interpretation – B.D., A.U.U.; Literature Search – B.D., S.O.; Writing Manuscript – B.D., S.O.; Critical Review – B.D., S.O., A.U.U.

**Declaration of Interests:** The author has no conflicts of interest to declare.

Funding: The authors declare that this study received no financial support.

#### References

- Kwan JYY, Famiyeh P, Su J, et al. Development and validation of a risk model for breast cancer-related lymphedema. *JAMA Netw Open*. 2020;3(11):e2024373. [CrossRef]
- Zhao H, Wu Y, Tao Y, et al. 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. 2022;45(1):70-82. [CrossRef]
- He L, Qu H, Wu Q, Song Y. Lymphedema in survivors of breast cancer. Oncol Lett. 2020;19(3):2085-2096. [CrossRef]
- Republic of Turkey Ministry of Health. Turkey national cancer control program 2018-2023; Published April 18, 2022. https://hsgm.saglik.gov.tr/ depo/birimler/kanser-Db/Dokumanlar/Raporlar/Turkey\_NCCP\_18\_April 2022.pdf. Accessed October 2024.
- 5. Yılmaz E, Coşkun T. Upper extremity problems and quality of life in patients with breast cancer. *BTDMJB*. 2019;15(1):29-37. [CrossRef]
- National Cancer Institute. Lymphedema (PDQ\*) health professional version. https://www.cancer.gov/about-cancer/treatment/side-effects/lymphedema/lymphedema-hp-pdq. Accessed May 11, 2023.
- Executive Committee. The diagnosis and treatment of peripheral lymphedema: 2016 Consensus Document of the International Society of Lymphology. Lymphology. 2016;49(4):170-184. https://pubmed.ncbi.nlm. nih.gov/29908550/. Accessed May 11, 2023.
- 8. Yalav O, Demircan O, Sakman G, Eray IC, Melek E, Suzan Z. Evaluation of safety and efficacy of the sentinel lymph node biopsy in patients with early-stage breast cancer without axillary involvement. *J Breast Health*. 2013;9(1):23-28.
- Zhao H, Wu Y, Zhou C, Li W, Li X, Chen L. Breast cancer-related lymphedema patient and healthcare professional experiences in lymphedema selfmanagement: A qualitative study. Support Care Cancer. 2021;29(12):8027-8044. [CrossRef]
- Best practice for the management of lymphoedema international consensus;
   2006. London: MEP Ltd. https://woundsinternational.com/consensus-documents/best-practice-for-the-management-of-lymphoedema-an-international-consensus/.
- 11. Deveci Z, Karayurt Ö, Bilik O, Eyigör S. Development of the breast cancer related lymphedema self-care scale. *Clin Nurs Res.* 2023;32(1):221-232. [CrossRef]
- EQUATOR Network. https://www.equator-network.org/. Accessed May 11, 2023.
- 13. Alcorso J, Sherman KA, Koelmeyer L, Mackie H, Boyages J. Psychosocial factors associated with adherence for self-management behaviors in women with breast cancer—related lymphedema. *Support Care Cancer*. 2016;24(1):139-146. [CrossRef]
- 14. Temür K, Kapucu S. Meme kanseri ilişkili lenfödem gelişimini önlemede ve yaşam kalitesini yükseltmede etkin yöntem: kendi kendine lenfödem yönetimi. *Osmangazi Tıp Derg.* 2018;40(1):121-129. [CrossRef]
- Perdomo M, Davies C, Levenhagen K, Ryans K, Gilchrist L. Patient education for breast cancer-related lymphedema: a systematic review. J Cancer Surviv. 2023;17(2):384-398. [CrossRef]
- Kuruvilla AS, Krajewski A, Li X, et al. Risk factors associated with postmastectomy breast cancer lymphedema: A multicenter retrospective analysis. *Ann Plast Surg.* 2022;88(3)(suppl 3):S239-S245. [CrossRef]
- Fu MR, Chen CM, Haber J, Guth AA, Axelrod D. The effect of providing information about lymphedema on the cognitive and symptom outcomes of breast cancer survivors. *Ann Surg Oncol*. 2010;17(7):1847-1853. [CrossRef]
- Acebedo JC, Haas BK, Hermanns M. Breast cancer–related lymphedema in Hispanic women: A phenomenological study. J Transcult Nurs. 2021;32(1):41-49. [CrossRef]
- Arikan Dönmez A, Kuru Alici N, Borman P. Lived experiences for supportive care needs of women with breast cancer-related lymphedema: A phenomenological study. Clin Nurs Res. 2021;30(6):799-808. [CrossRef]
- 20. Ostby PL, Armer JM, Smith K, Stewart BR. Patient perceptions of barriers to self-management of breast cancer–related lymphedema. *West J Nurs Res.* 2018;40(12):1800-1817. [CrossRef]
- 21. Park JH, Lee WH, Chung HS. Incidence and risk factors of breast cancer lymphoedema. *J Clin Nurs*. 2008;17(11):1450-1459. [CrossRef]
- Lee YM, Mak SS, Tse SM, Chan SJ. Lymphoedema care of breast cancer patients in a breast care clinic: A survey of knowledge and health practice. Support Care Cancer. 2001;9(8):634-641. [CrossRef]

- 23. Thomas-MacLean R, Miedema B, Tatemichi SR. Breast cancer-related lymphedema: women's experiences with an underestimated condition. *Can Fam Physician*. 2005;51(2):246-247. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1479444/.
- 24. Paskett ED, Stark N. Lymphedema: knowledge, treatment and impact among breast survivors. *Breast J.* 2000;6(5):373-378. [CrossRef]
- Douglass J, Graves P, Gordon S. Self-care for management of secondary lymphedema: A systematic review. PLOS Negl Trop Dis. 2016; 10(6):e0004740. [CrossRef]
- 26. Wang Y, Wei T, Li M, et al. Factors influencing the self-management of breast cancer-related lymphedema: A meta-synthesis of qualitative studies. *Cancer Nurs*. 2024. [CrossRef]
- Chen CJ, Hong LCH, Xu WZH, et al. Qualitative research on self-management of lymphedema after breast cancer surgery. *Chin Clin Nurs*. 2023;15(2):98-102.
- 28. Donahue PMC, MacKenzie A, Filipovic A, Koelmeyer L. Advances in the prevention and treatment of breast cancer-related lymphedema. *Breast Cancer Res Treat*. 2023;200(1):1-14. [CrossRef]