

Awareness of lymphedema risk management behaviors and associated factors among breast cancer survivors: Results from a cross-sectional survey

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Abstract

Aim: Breast cancer-related lymphedema (BCRL) is a disabling complication that can develop following breast cancer surgery months or even years after treatment ends. The effective management of BCRL requires adhering to simple risk-reduction strategies. The study aim was to assess the awareness and knowledge of lymphedema risk-management behaviors among breast cancer survivors and identify factors that affect it.

Material and Methods: This study was conducted on 250 survivors of breast cancer. Demographic information, treatment details, time since surgery, duration and stage of lymphedema were recorded. Lymphedema education, knowledge about risk-minimization recommendations, and information sources were questioned using a survey. A multiple linear regression was used to identify predictors of lymphedema awareness.

Results: Just over half (53.6%) of the patients had adequate lymphedema awareness (score \geq 8). BCRL was detected in 121 (48.4%) patients. Awareness scores varied by age, education level, body mass index, receiving chemotherapy and radiotherapy, and a previous BCRL treatment (all $p < 0.05$). Citing physiatrists as an information source reflected higher levels of awareness. Educational level and axillary lymph node dissection were positive predictors; time since surgery was the only negative predictor of lymphedema awareness.

Conclusion: This study highlights the lack of lymphedema awareness among survivors of breast cancer. Accurate, timely, individualized training programs can improve knowledge and compliance of lymphedema risk management behaviors.

Keywords: Awareness; breast cancer; education; lymphedema

INTRODUCTION

Breast cancer is the most frequently diagnosed cancer among women and the leading cause of cancer-related death in females worldwide (1). Every year, over 1.5 million women (25% of all women diagnosed with cancer) are diagnosed as having breast cancer throughout the world (2,3). As the improvements in early diagnosis and advanced medical therapies reduce breast cancer mortality, more patients with breast cancer are affected by the late and long-term adverse effects of cancer treatment, which can lead to serious physical and psychological disabilities (4).

Lymphedema is a chronic and progressive disorder of the lymphatic system, characterized by persistent swelling

of one or more parts of the body, due to impairments of lymphatic drainage (5). In developed countries, the most common cause of upper-limb lymphedema is breast cancer (3-6). In a recent meta-analysis, the incidence of breast cancer-related lymphedema (BCRL) was 21.4% (7). In Turkey, the rate of BCRL has been estimated as 7% to 28% in small-scale studies (8). Breast cancer surgery, removal of axillary lymph nodes, radiotherapy, chemotherapy, and higher body mass index (BMI) can lead to obstruction of lymphatic drainage and the abnormal accumulation of protein-rich lymph fluid within the interstitial space (3-8). Lymphedema may develop at any time following breast cancer treatment and cause more serious complications that may impact a woman's body image and impair quality

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of life and functional outcomes (9). Therefore, awareness on lymphedema risk and risk reduction strategies is a critical component of care for patients with breast cancer who are at increased risk for developing lymphedema (10).

A Breast Health Global Initiative 2013 consensus statement revealed the importance of education and awareness of lymphedema and recommended community awareness programs along with patient and health professional education (11). In many countries, national breast cancer organisations publish guidelines that recommend lifetime behaviors to minimize lymphedema risk. Obesity, weight gain after diagnosis, upper extremity infections, heavy lifting, injury or trauma to the affected arm, overuse of the limb, and air travel are potentially evitable risk factors in these guidelines (12).

Information sources are critical for patients with cancer to provide sufficient and appropriate information in the decision-making and self-care process. Information is available from various sources including books, brochures, health professionals (physiatrists, physical therapists, nurses, general surgeons, family medicine physicians, medical and radiation oncologists), relatives or friends who have experienced breast cancer, and the internet (13,14).

Several studies have evaluated education, lymphedema prevention, and management knowledge of patients after breast cancer surgery and treatment (13-25). Most of their findings underscored the inadequate knowledge level, and emphasized the need to improve lymphedema education and knowledge among all breast cancer survivors (13-17,21,23). Fu et al. found a correlation between lymphedema knowledge and risk of developing the condition (21). Also, some stressed the potential need for educational interventions to strengthen physician knowledge for the management of lymphedema (13,14,16,22,24). The aim of the study was to assess the awareness and knowledge of lymphedema risk-management behaviors among survivors of breast cancer and identify demographic and clinical factors that affect it.

MATERIAL and METHODS

Patient population

This cross-sectional study was conducted with women who had undergone mastectomy or breast conserving surgery with unilateral axillary lymph node dissection or sentinel lymph node biopsy for breast cancer. A total of 265 patients were recruited between May 2018 and July 2019. They were asked to participate in a study that collected information about lymphedema-related education, lymphedema knowledge of risk-minimization behaviors, and the sources of information used. Fifteen patients did not wish to join the study, thus, a total of 250 women were considered for the study. Inclusion criteria were women aged between 18-65 years with a history of breast cancer surgery and being referred to the lymphedema rehabilitation unit of the physical medicine

and rehabilitation (PMR) department. The authors determined the number of samples for this study by referring to the sample size of previous studies conducted in other countries (13,15).

Clinical records

Sociodemographic information and treatment details including age, education level, BMI, smoking habit, time since surgery, type of surgery (modified radical mastectomy, radical mastectomy) and axillary node status [axillary lymph node dissection (ALND), sentinel lymph node biopsy (SLNB)], chemotherapy and radiotherapy receiving status, duration of lymphedema, clinical lymph-edema stage, information sources about lymphedema, and previous clinical diagnosis and treatment for BCRL status were obtained. All patients were assessed according to the criteria of the 2016 Consensus Document of the International Society of Lymphology (26). A single researcher (ST) undertook the clinical assessments of lymphedema.

Lymphedema-related education

The first two survey items were used to assess lymphedema education, similar to items used in prior research by Choi et al. (10). Patients were asked whether they knew about lymphedema and if they had been given information about the possibility of lymphedema at the time of breast cancer diagnosis or before and after breast cancer surgery from healthcare professionals.

Lymphedema-related knowledge

Twelve survey items based on the guidelines of the Anatolian Lymphedema Association (www.lenfodemdernegi.org.tr) were used to assess current knowledge for each risk-minimizing behavior (27). All of the patients were asked about potential risk factors for the development of lymphedema, which occurs in the affected arm (injections, blood taking or tension measuring, bad skin and nail care, excessive heat, wearing gloves for any work, trauma, tight clothing or wearing jewelry, heavy lifting, and overtiring the upper extremities, weight gain or obesity) and timing of lymphedema after treatment for breast cancer. The last question asked about the disciplines that treat lymphedema. The survey instrument was designed from a review of the current literature and adapted as necessary by the authors (13-15). The preliminary draft of the questionnaire was pre-tested with several support groups of breast cancer survivors and feedback was obtained to refine the questionnaire relative to content and ease of comprehension.

All questions were closed-ended and answered using a simple "yes" or "no." Correct answers were scored as 1 and incorrect answers were scored as 0. The minimum score is 0 and the maximum score is 13 ($\alpha = 0.84$, indicating acceptable item reliability). The median score was used to classify the awareness level of the respondents into two groups (adequate and not inadequate). With regards to knowledge-related questions, the overall median score of knowledge for all the participants was 8. Respondents

who scored median and above the median score of the correctly answered questions were classified as adequate, less than median score of correct answers was classified as inadequate.

Sources of lymphedema information

Participants were asked about the lymphedema information sources they used, including other breast cancer survivors, relatives, health professionals (general surgeon, oncologist, physiatrist, radiation oncologist, family medicine physician) and external sources (books, internet) similar to previous study of Bosompra et al. (13). The study protocol was approved by the Faculty Research Ethics Committee with the decision numbered 10840098-604.01.01-E.18662. Written informed consent was obtained from each patient. The study was conducted in accordance with the principles of the Declaration of Helsinki.

Statistical Analysis

Data were analyzed using the IBM-SPSS for Windows version 23.0 software package (IBM Corp., Armonk, NY, USA). The Shapiro-Wilk test was used to evaluate the normality of data distribution. Frequency, percentage, mean, median, and standard deviation were used for descriptive statistics. For two-group comparisons (patients with lymphedema vs. without lymphedema), we used the Chi-square test and Fisher exact test for categorical variables, the independent sample t test for continuous data if normal distribution of variables existed, and the Mann-Whitney U test in other cases. A multiple linear regression (MLR) model was used to identify independent predictors of lymphedema awareness and to determine confounding effects between potentially independent predictors. A stepwise method was used to construct MLR models. Variables could be entered or removed from the model depending on the significance (probability) of the F value. A variable was entered into the model if the probability of its score statistic was less than the entry value (0.05), and it was removed if the probability was greater than the removal value (0.1). Model fit was assessed using appropriate and goodness-of-fit statistics. Multicollinearity was tested using a variance inflation factor (VIF), and autocorrelation was tested using Durbin-Watson statistics. Results with a p value of <0.05 were considered statistically significant.

RESULTS

Two hundred fifty patients with a mean age of 51.43 + 8.60 (range, 28-65) years were recruited to the study. The majority of respondents (54%) were aged 50 years or older. The mean BMI was 28.57±4.17 kg/m²; 38.8% of respondents had a BMI higher than 30 kg/m². More than half of the patients (56%) graduated from high school or had university/doctorate education. The median time since surgery was 48.48 (range, 2.23- 248.53) months. More than half of the respondents had undergone breast-conserving surgery (57.6%) and ALND (56.8%). Two

hundred eighteen patients (87.2%) received chemotherapy and 208 patients (83.2%) received radiotherapy. Among the participants, BCRL was detected in 121 (48.4%) patients; 70 (57.9%) had reversible BCRL, 43 (35.5%) had spontaneous irreversible BCRL, and 8 (6.6%) patients had elephantiasis. Ninety-two patients (36.8%) had a current diagnosis of BCRL and 44 (17.6%) patients had previously received treatment for BCRL (Table 1).

The median lymphedema awareness score was 8 (range 3-12). Just over half (53.6%) of the patients scored the median (score ≥8) and above in the questions and were considered as having adequate awareness. Patients with BMI less than 30 kg/m², under the age of 50 years, and those who graduated from high school and more were significantly more aware of lymphedema (p=0.038, p=0.001, p<0.001, respectively). Patients who received chemotherapy, radiotherapy and reported previous BCRL treatment were more aware of lymphedema (p=0.007, p=0.027, p<0.001). Women who received information from physiatrists were more aware of BCRL than those who did not receive information from these professionals (p<0.001). Citing relatives as an information source reflected poorer awareness than in those who did not cite this source (p=0.002). The demographic and clinical characteristics of the patients in regard to lymphedema awareness are shown in Table 1.

The status of education and knowledge about the preventive behaviors and management of BCRL was evaluated in a 15-question survey (Table 2). Table 2 provides the numbers and percentages of participants who correctly answered each knowledge item by lymphedema status. For the education part of the survey, patients with lymphedema more frequently reported receiving information about the possibility of lymphedema at the time of breast cancer diagnosis or before and after breast cancer surgery from health professionals (p<0.001). For the knowledge part of the survey, we calculated a total awareness score (range: 0–13). Patients with lymphedema were significantly more aware of the timing of lymphedema following breast cancer surgery or treatment and about which medical discipline would manage lymphedema treatment (p=0.001, p<0.001). No difference was found in the other items between patients with and without lymphedema. The median lymphedema awareness score was 8 (range 3-12); no difference was detected between two groups in this regard.

A stepwise MLR model was applied to learn which variables were independent predictors of awareness about the recommended behaviors. Significant positive predictors were education level (b=0.484, p<0.001) and ALND surgery (b=0.220, p<0.001). Time since surgery (b= -0.153, p=0.010) was the only significant negative predictor of lymphedema awareness (Table 3) (Adjusted R Square= 0.263, F= 30.657, p=0.000, Durbin Watson= 1.875).

Table 1. The demographic and clinical characteristics of the patients in regard to lymphedema awareness

	Total n=250	Adequate Awareness (score≥8) n= 129 (51.6%)	Inadequate Awareness (score<8) n=121 (48.4%)	p
Age (years), n (%)				
< 50	115 (46.0)	75 (56.0)	40 (34.5)	0.001
≥ 50	135 (54.0)	59 (44.0)	76 (65.5)	
BMI (kg/m²), n (%)				
<30	153 (61.2)	90 (67.2)	63 (54.3)	0.038
≥30	97 (38.8)	44 (32.8)	53 (45.7)	
Education, n (%)				
Secondary school and less	110 (44.0)	33 (24.6)	77 (66.4)	<0.001
High school and more	140 (56.0)	101 (75.4)	39 (36.6)	
Time since surgery (months; median [min-max])	48.48 [2.23-248.53]	44.10 [4.57-236.73]	51.90 [2.23-248.53]	0.068
Smoking status, n (%)				
non-smoker	200 (80.0)	102 (76.1)	98 (84.5)	0.099
currently/ex-smoker	50 (20.0)	32 (23.9)	18 (15.5)	
Surgery type, n (%)				
Breast-conserving surgery	144 (57.6)	74 (55.2)	70 (60.3)	0.414
Mastectomy	106 (42.4)	60 (44.8)	46 (39.7)	
Axillary node status, n (%)				
SLNB	108 (43.2)	53 (39.6)	55 (47.4)	0.211
ALDN	142 (56.8)	81 (60.4)	61 (52.6)	
CT treatment (+), n (%)	218 (87.2)	124 (92.5)	94 (81.0)	0.007
RT treatment (+), n (%)	208 (83.2)	118 (88.1)	90 (77.6)	0.027
Lymphedema (+), n (%)	121 (48.4)	70 (52.2)	51 (44.0)	0.192
Duration of lymphedema (months; mean±SD)	30.40 [1-187.67]	27.86 [1-183.63]	45.63 [1-187.67]	0.090
Self-report of lymphedema clinical diagnosis	92 (36.8)	56 (41.8)	36 (31.0)	0.079
Self-report of lymphedema treatment	44 (17.6)	36 (26.9)	8 (6.9)	<0.001
ILS - lymphedema stage, n (%)				
subclinical	129 (51.6)	64 (47.8)	65 (56.0)	0.568
reversible	70 (28.0)	39 (29.1)	31 (26.7)	
spontaneous irreversible	43 (17.2)	26 (19.4)	17 (14.7)	
elephantiasis	8 (3.2)	5 (3.7)	3 (2.6)	
Source of information about lymphedema				
Books	7 (2.8)	3 (2.2)	4 (3.4)	0.707
Internet	27 (10.8)	17 (12.7)	10 (8.6)	0.302
Physiatrist	113 (45.2)	93 (69.4)	20 (17.2)	<0.001
Oncologist	66 (26.4)	40 (29.9)	26 (22.4)	0.183
General Surgeon	140 (56.0)	81 (60.4)	59 (50.9)	0.128
Radiation oncologist	26 (10.4)	16 (11.9)	10 (8.6)	0.391
Family medicine physician	7 (2.8)	4 (3.0)	3 (2.6)	1.000
Other breast cancer survivors	42 (16.8)	23 (17.2)	19 (16.4)	0.869
Relatives	46 (18.4)	15 (11.2)	31 (26.7)	0.002

n: Number of subjects, BMI: Body mass index, ALND: Axillary lymph node dissection, SLNB: sentinel lymph node biopsy, CT: chemotherapy, RT: radiotherapy, SD: standard deviation; p <0.05 was considered statistically significant

Table 2. The demographic and clinical characteristics of the patients in regard to lymphedema awareness

	Total n=250	Lymphedema (+) n=121	No Lymphedema n=129	P
1. Do you know about lymphedema?	206 (82.4)	98 (81.0)	108 (83.7)	0.571
2. Did you receive information about the possibility of lymphedema at the time of breast cancer diagnosis or before and after breast cancer surgery from health care professionals?	204 (81.6)	110 (90.9)	94 (72.9)	<0.001
3. Can lymphedema occur at any time following breast cancer surgery?	166 (66.4)	93 (76.9)	73 (56.6)	0.001
4. Do you think which department can manage lymphedema?				
Physical medicine and rehabilitation	171 (68.4)	99 (81.8)	72(55.8)	<0.001
General surgery	70 (28.0)	30 (24.8)	40 (31.0)	0.274
Oncology	13 (5.2)	5 (4.1)	8 (6.2)	0.461
No idea	19 (7.6)	7 (5.8)	12 (9.3)	0.294
5. Is it possible that blood pressure checks, injections, vaccinations or blood drawing in the affected arm(s) can increase the risk of lymphedema occurrence?	240 (96.0)	116 (95.9)	124 (96.1)	0.999
6. Is it possible that poor hygiene, skin and nail care of the affected arm can increase the risk of lymphedema occurrence?	188 (75.2)	88 (72.7)	100 (77.5)	0.381
7. Is it possible that any type of trauma to the affected arm (e.g. bruises, cuts, sunburn, insect bites, cat scratches) can increase the risk of lymphedema occurrence?	225 (90.0)	107 (88.4)	118 (91.5)	0.423
8. Is it possible that wearing tight bras, jewellery or elastic bands around affected chest, arm(s) or fingers can increase the risk of lymphedema occurrence?	98 (39.2)	45 (37.2)	53 (41.1)	0.528
9. Is it possible that heavy lifting and overtiring the affected arm can increase the risk of lymphedema occurrence?	228 (91.2)	107 (88.4)	121 (93.8)	0.134
10. Is it possible that weight gain or obesity can increase the risk of lymphedema occurrence?	66 (26.4)	29 (24.0)	37 (28.7)	0.398
11. Is it possible that excessive heat on arm (e.g. hot packs, hot baths, hot showers, saunas and hot tubs) can increase the risk of lymphedema occurrence?	99 (39.6)	52 (43.0)	47 (36.4)	0.291
12. Is it possible that wearing protective gloves for housework, gardening or any work can reduce the risk of lymphedema occurrence?	144 (57.6)	69 (57.0)	75 (58.1)	0.859
13. Is it possible that wearing a well-fitted compression sleeve on airplane flights can reduce the risk of lymphedema occurrence?	92 (36.8)	51 (42.1)	41 (31.8)	0.089
14. Do you get medical advice immediately if you notice swelling, rash, itching, redness, pain, increase of temperature or fever?	243 (97.2)	116 (95.9)	127 (98.4)	0.269
15. Do you recommend exercises like walking, swimming, light aerobics, bike riding or yoga?	171 (68.4)	81 (66.9)	90 (69.8)	0.631
Total Lymphedema awareness score (max. 13 points), median [min-max]	8 [3-12]	8 [3-12]	7 [3-12]	0.193

* The data were express " yes" answers, n: Number of subjects, Data are expressed as median and min-max; p <0.05 was considered statistically significant

Table 3. Multiple linear regression analysis of predictors of the lymphedema awareness

Predictor	Standardised Coefficients		p	95% Confidence Interval for B		Collinearity Statistics (VIF)
	(Beta)	t		Lower Bound	Upper Bound	
(Constant)		9.224	<0.001	4.208	6.494	
Education level	0.484	8.779	<0.001	0.819	1.292	1.026
ALND surgery	0.220	3.723	<0.001	0.528	1.716	1.176
Time since surgery	-0.153	-2.593	0.010	-0.014	-0.002	1.177

VIF: variance inflation factor, Adjusted R Square= 0.263, F= 30.657, p<0.001, Durbin Watson= 1.875

DISCUSSION

Despite continuous advances in the detection and treatment of breast cancer, BCRL is still a common post-operative problem among survivors of breast cancer. It is very important to make an early diagnosis, to know and adhere to recommended lymphedema risk management guidelines because chronic, advanced-stage BCRL is less responsive to treatment (9,10,13-16,20,21).

This cross-sectional study evaluated the knowledge level of survivors of breast cancer about BCRL risk management behaviors and identified factors that affected awareness in a breast cancer center of university hospital. In the present study, 51.6% of patients had adequate lymphedema awareness. Awareness score varied by demographic characteristics such as age, education level and BMI.

Patients under the age of 50 years had better awareness of lymphedema. The effect of increasing age is a possible trend of poorer awareness. Kwan et al. found that older age was significantly associated with a lower awareness score (20). Choi et al. indicated that age was one of the risk factors affecting awareness and cognitive decline in the aging population (15). The above results show that age-specific education will provide an optimal benefit in improving knowledge among patients with breast cancer on lymphedema risk and risk-reduction practices. Also brochures, practice-based lymphedema educational programs or videos may help to keep information fresh in the patient's mind.

In our study, patients with BMI of less than 30 kg/m² were also more aware of BCRL. Patients showed the lowest level of awareness (26.4%) on the question about weight gain regarding the increased risk of lymphedema development. A similar result was obtained in Choi et al.'s study. They emphasized a lack of information about weight gain even after the diagnosis of lymph-edema (15). Optimal weight management programs can be implemented clinically with breast cancer diagnosis for modifying a patient's risk for BCRL.

Lymphedema may develop within days, months or even years after surgery. This will depend on the treatment regimens and preventive practices of the patient.

Previous studies identified that mastectomy, extent of axillary dissection, radiotherapy, chemotherapy, and the presence of positive nodes were significantly associated with an increased risk of developing BCRL (3,6-8). Among these, disease duration, chemotherapy, and previous BCRL treatment were reported as affecting factors of lymphedema awareness (15). In our study, patients who had chemotherapy or radiotherapy and treatment for BCRL were significantly more aware of lymphedema. In MLR analysis, time since surgery was a negative predictor, and ALND surgery and education level were positive predictors of awareness. Similarly, Choi et al. found that patients who had lymph node dissection, chemotherapy or radiotherapy, and a previous lymphedema diagnosis and treatment, all had a significantly greater awareness of BCRL. They also showed that the factors that affected this awareness were chemotherapy, lymphedema treatment, duration of illness, and age (15). Patients with high educational levels and short disease duration may have greater exposure to healthcare professionals during follow-up visits and adjuvant therapy. Also, they may have a better chance for receiving information from physiatrists and physiotherapists during BCRL treatment and this may have had a positive effect on their awareness of lymphedema.

Provision of cancer-related education and information plays a major role in the treatment. The main aim behind information provision is to prepare patients with cancer for treatment, to increase their adherence to treatment and their strength of living with the disease, to ensure recovery, to make interactions with health professionals, and to help them cope with the long-term effects of treatment (28). Zou et al. indicated that BCRL could be tracked accurately and treated effectively by educating patients on the potential risk factors and ensuring that they realise the importance of early detection and treatment (29). Ridner et al. suggested that pre-treatment lymphedema education might improve the recall of educational information about lymphedema in survivors of breast cancer, and risk management education might influence the risk of developing lymphedema (30). Sherman et al. showed that obtaining information about lymphedema three months after surgery and receiving

information from nursing staff were significant predictors of performing risk-minimization recommendations among patients recently diagnosed as having breast cancer (14). Previous studies determined inadequate education for lymphedema (13-16). In a study from Turkey, Borman et al. reported that only 19% of patients with breast cancer who had been referred to their lymphedema rehabilitation unit had been educated about lymphedema before (16). Similarly, Choi et al. determined inadequate education for lymphedema in Korean patients with breast cancer (15). In the present study, although we found that more than 80% of patients with breast cancer received information about the possibility of lymphedema from the medical staff at the time of breast cancer diagnosis or before and after breast cancer surgery, the level of lymphedema knowledge about prevention practices was low with a median score 8 (maximum score 13) (mean 7.57, SD \pm 2.25). Similarly, Lee et al. conducted a population survey in Hong Kong about lymphedema knowledge on lymphedema prevention and care and found that the majority (82.5 %) of patients knew that they were at risk of developing lymphedema, but the level of lymphedema knowledge about prevention practices was low (mean 4.07, SD \pm 2.35) (10). This reveals the need for educational programs targeting patients and health professionals. The effectiveness of these programs may be improved through standardization and individualization.

Educating patients about lymphedema risk management was demonstrated to increase the adherence to the recommended behaviors and decreased the risk of developing the condition (17,19,21). Previous studies evaluated lymphedema knowledge or awareness using a score obtained from surveys or interview data and they generally reported low levels (15-20). In our study, a low awareness level was observed in both patients with and without BCRL and no difference was detected between the two groups. Similar to our results, Kwan et al. reported low knowledge levels with a median score of 4 (maximum score 7) (mean 3.11, SD \pm 2.92) and no difference was detected between women with and without BCRL (20). On the other hand, Bosompra et al. found a significantly higher mean score among patients reporting any swelling versus no swelling (8.5 vs. 5.4) (13). In our study, some questions regarding the risk factors of lymphedema, such as wearing tight clothes, weight gain, excessive heat, and wearing a well-fitted compression sleeve on airplane flights were correctly answered by less than fifty percent of patients on the questionnaire. Only one question about the timing of lymphedema development following breast cancer surgery reached statistical significance between patients with and without lymphedema (76.9% vs. 56.6%). These results suggest that patients generally did not have enough and proper lymphedema prevention and management information, even they developed lymphedema.

The current study also analyzed the source of lymphedema information accessed by women following a breast cancer diagnosis. General surgeons and physiatrists

were the most used information sources, but only receiving information from physiatrists was related with a significantly increased awareness level. The question about medical department that managed lymphedema (PMR) was answered correctly by 68.4% of the patients. This revealed that much of the information exchange occurs in the perioperative period and during follow-up visits with general surgeons and PMR staff. Relatives were a source of information used by almost 18.4% of the patients; however, it was related with low awareness levels. This demonstrated the accuracy of the information provided by healthcare professionals and the importance of providing patient-specific recommendations based on the current stage of lymphedema. In our country, Turkey, Borman et al. formed the first multidisciplinary association that educated both patients and health professionals about the early diagnosis and prompt and proper management of BCRL (16). We hope that this program will be most useful in raising awareness of lymphedema and will also create more effective health communication and a wider network of healthcare providers throughout the breast cancer treatment process pertaining to lymphedema.

The small number of subjects presenting to a university hospital who were analyzed in a cross-sectional study in design is a limitation of this study. In present study, patients showed a low level of awareness about risk reduction recommendations, but we did not follow patients up to determine whether they adhered to them. Also some behaviors were considerably less known but we did not identify the underlying factors. We did not use standardized educational programs with standard timing to our patients or observe the effects on controlling lymphedema and changes in the awareness level of patients.

CONCLUSION

In conclusion, the study highlighted a lack of lymphedema awareness among survivors of breast cancer. Our research indicates that there are some parameters that influence awareness, such as age, education level, BMI, receiving chemotherapy and radiotherapy, time since surgery, and previous lymphedema treatment. Healthcare providers need to provide accurate, timely, and individualized educational programs that address the special needs of each patient to enhance adherence to lymphedema risk-reduction behaviors, decrease BCRL risks, and improve outcomes. There is a need for a multidisciplinary team approach to share and solve the problems of patients with lymphedema and to increase awareness in society.

Competing interests: The authors declare that they have no competing interest.

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