

Clinical Awareness and Knowledge of Breast Cancer-Related Lymphedema among a Group of Psychiatrists in Turkey – An Online Survey

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ABSTRACT

Background: The point-of-view and role of psychiatrists are important in the clinical care of breast-cancer-related-lymphedema (BCRL) patients to set up management and rehabilitation strategies. **Aim:** The aim of this study was to determine the awareness and knowledge of BCRL among a group of psychiatrists regarding its causes, symptoms, treatment, and management in Turkey. **Subjects and Methods:** The participants were asked to answer a 10-min web survey, including 19 questions. In addition to their demographical and logistic properties, the questionnaire elicited data on the knowledge, education, and awareness of the psychiatrists on the diagnosis and treatment of BCRL. **Results:** In total, 127 female and 44 male psychiatrists completed the survey. Also, 71% of the participants were aged between 31 and 50 years, mostly working in metropolises and tertiary hospitals for more than 5 years. Further, 63.7% of the participants expressed that they had knowledge about BCRL; however, detailed knowledge of lymphedema treatment was low, as 67.9% of the psychiatrists reported that they had no comprehensive information about complete-decongestive-therapy. Nearly half of the participants did not believe that once lymphedema has clinically manifested, a patient can eventually be treated for BCRL. Also, 87% of the participants had attended less than two educational events related to BCRL in the past 5 years. In all, 94.7% of the physicians determined a great need for education and awareness of the current literature about BCRL. **Conclusion:** The awareness and knowledge of lymphedema is moderate but detailed information, knowledge, and education about lymphedema and its treatment are low among a group of psychiatrists. With the growing number of breast cancer survivors, psychiatrists' awareness and education about BCRL are crucial to improve the quality of care of patients.

KEYWORDS: Awareness, knowledge, lymphedema, psychiatrist

INTRODUCTION

Breast cancer is the most common type of cancer and the leading cause of cancer-related deaths in women worldwide.^[1,2] Improvements in the early diagnosis and treatment of breast cancer have resulted in an increased number of survivors. Unfortunately, the rate of side effects including breast cancer-related lymphedema (BCRL) increases as women survive longer after the diagnosis and treatment of breast cancer. As the side effects of cancer treatments may lead to significant

long-term physical and psychosocial disabilities, the maintenance of the overall health, functional status, and quality of life have been a major concern.^[3]

Lymphedema is a chronic condition identified as the accumulation of protein-rich fluid in the interstitial tissues

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that can arise at any time after breast cancer surgery with or without radiation therapy. Lymphedema has been determined in up to 70% of breast cancer survivors, depending on the diagnostic criteria, type of surgery, the addition of radiation therapy, body mass index (BMI), and assessment duration after surgery.^[4] Although the physical and psychosocial burden of lymphedema has been indicated to significantly impair the overall quality of life, it is still under-recognized and under-treated in many health centers.^[4,5]

Lack of awareness and medical expertise in the diagnosis and treatment of this condition, and the tendency of clinicians to ignore lymphedema in patients who have had cancer surgery, make this condition more problematic.^[6] The point of view and role of physical medicine and rehabilitation (PMR) specialists, also known as physiatrists, are important in the clinical care of BCRL patients. PMR specialist is responsible for the assessment of patients to make an accurate differential diagnosis and set up appropriate management strategies. Therefore, PMR specialists should have comprehensive knowledge about the pathophysiology, epidemiology, diagnostic and preventive measures as well as therapeutic approaches to lymphedema.^[6,7]

Several studies have indicated the importance of awareness and education about lymphedema among patients in both developing and developed countries,^[5,8-13] but there are very few studies that have reported the awareness and education about this condition among physicians. The previous reports have included mostly general practitioners, surgeons, oncologists, or radiation oncologists.^[14-17] As far as we have known, no study has been conducted on the awareness and knowledge about BCRL among PMR specialists who deal with the diagnosis and treatment of patients with BCRL.

The aim of this study was to determine the level of awareness and clinical knowledge of a group of physiatrists about the risk factors, symptoms, and treatment of BCRL.

MATERIALS AND METHODS

This cross-sectional study was based on an online survey, announced on the website of the national society of PMR. The physiatrists, who voluntarily agreed to participate in this study, were directed to a secure study-designated mailbox by a link. The physiatrists who volunteered to participate in the study and completed all survey questions were included. The study was approved by the Local Ethics Committee (GO 14/512-10). Informed consent was obtained on the first page of the online survey by checking the consent box.

To evaluate the physiatrists' awareness and knowledge about BRCL, the survey which was designed by Sarkar *et al.*,^[17] was used after being translated into Turkish and tested for language validity. It includes 17 items on demographical characteristics (age, gender, years, and current clinical area of practice, number of patients with BCRL whom they have treated over the past 12 months), awareness and knowledge about BCRL in regard to different and multiple indirect questions, education, and literature knowledge. The preliminary draft of the Turkish questionnaire had been pre-tested with a group of physiatrists and feedback had been obtained to refine the questionnaire relative to the content and is compatible with the characteristics of Turkish physicians. Additionally, we asked the following: (1) Have you ever heard about lymphedema? Have you got any information about this condition? (2) Please tell us about the location and type of the hospital you are still working. The answers to the first question were stated as follows: a) Never heard, b) I have heard, but do not have any information, c) I have heard but have very little information, d) I have heard and have information. The final survey, presented as a web link, consisted of 19 questions and took about 10 min to complete.

A knowledge score about BCRL was calculated based on the answers to questions #6–10, #12,13,16,17 about the risks, symptoms, and treatment options of BCRL, with the score ranging from –11 (lowest knowledge) to 32 (highest knowledge), for the list of questions and associated weights per question that comprised the overall knowledge score. The level of awareness of current scientific literature pertaining to the predisposing factors to BCRL and familiarity with the knowledge of diagnostic and therapeutic guidelines were calculated based on the answers with the score ranging from 1 to 5 (1 indicates no relevant knowledge, 5 indicates comprehensive knowledge).

Statistical analysis

All collected data from the web survey were checked periodically for data quality. The Kolmogorov–Smirnov test was used to determine whether the numerical variables showed normal distribution, and the homogeneity of the variance was examined by Levene's test. Descriptive characteristics of continuous variables were determined as mean \pm standard deviation (SD), whereas categorical variables were defined as frequencies. All data about the BCRL knowledge scores were compared with respect to participants' age, gender, years of clinical practice, and current clinical area of practice, by either independent samples *t*-test with Cohen's *d* as effect size or one-way analysis of variance (ANOVA) with eta-square as an

effect size. Statistical analyses were performed using the SPSS version 22.0 software. All tests of statistical significance were two-sided and considered statistically significant at the level of 0.05. The effect size was obtained as $f = 0.427$ according to the number of patients seen in the clinic based on the knowledge scores. As a result of the post-hoc power analysis performed with G power 3.1.9.2, the power of the study was found to be 99.89%.

RESULTS

A total of 127 female and 44 male psychiatrists replied to the questionnaire. Most participants were aged between 31 and 40 years (40.9%), followed by the age group of 41–50 years (29.8%). The majority of them were working in metropolises (83.6%) and tertiary hospitals (university or training and research hospitals) (52.6%) for more than 5 years (66.7%). The demographical characteristics of the participants are shown in Table 1. Although 63.7% of the participants declared that they had heard and had

information about BCRL, 36.3% of them had heard but had very little information about it.

Sixty-nine percent of the responders stated that they had seen less than 10 patients over the previous 12 months. One-third of the participants declared that they had no prior knowledge of the literature related to predisposing factors of BCRL, only 3.5% of them stated that they had detailed knowledge about this issue. Although 43.3% of the participants had not attended any conferences, workshops, seminars, or other educational events related to lymphedema in the past 5 years, 43.3% of them had attended one or two meetings. Also, 54.4% of them agreed that “once lymphedema has clinically manifested, eventually it can be treated”; however, 31.6% disagreed with this statement. Almost all responders (98.8%) agreed that educational work and raising awareness about lymphedema and its predisposing factors are needed in the medical community [Table 2].

The mean score of knowledge calculated based on the responses about incidence, anatomical areas, symptoms, assessment, and treatment of BCRL patients in clinical practice was 16.30 ± 3.83 (min–max 4–27). One-third of the participants guessed right the incidence of BRCL as 30–50%. Ninety-five percent of the subjects have heard about manual lymphatic drainage, 71.9% about multilayer lymphedema bandaging, and 90.6% about compression garments. However, 67.9% of the psychiatrists reported that they had no comprehensive information about complete decongestive therapy and less than 5% of the psychiatrists had familiarity and knowledge about the consensus papers or different guidelines on the treatment of lymphedema (question 17).

	<i>n</i> (%)
Gender	
Female	127 (74.3%)
Male	44 (25.7%)
Age groups	
20-25	5 (2.9%)
26-30	26 (15.2%)
31-40	70 (40.9%)
41-50	51 (29.8%)
51-60	16 (9.4%)
61-70	3 (1.8%)
Years of clinical practice	
<1 year	10 (5.8%)
1-5 years	47 (27.5%)
6-10 years	62 (36.3%)
16-20 years	30 (17.5%)
>20 years	22 (12.9%)
Location of hospital	
1 st Area - Metropol (ice) s (provinces with metropolitan municipalities)	143 (83.6%)
2 nd Area - Other Cities	20 (11.7%)
3 rd Area – Districts	8 (4.7%)
Type of hospital	
University Hospital	53 (31%)
Research Hospital	37 (21.6%)
Other Public Hospitals	21 (12.3%)
Private Clinics	1 (0.6%)
Private Hospitals	33 (19.3%)
Private Health Consulting Centers	26 (15.2%)

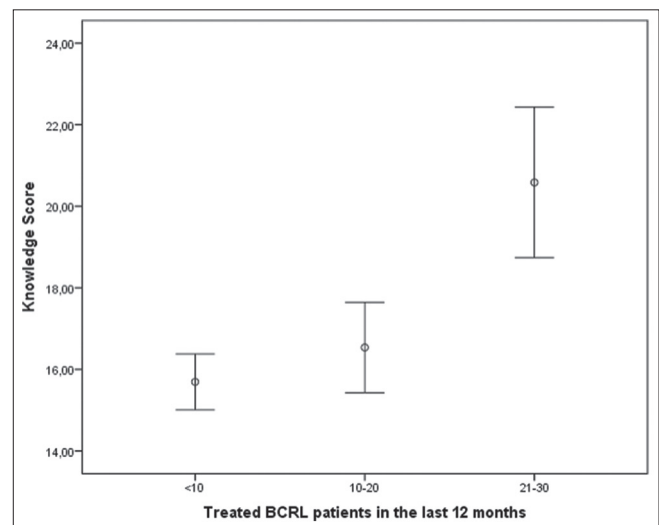


Figure 1: Comparison of knowledge score in psychiatrists according to number of patients treated in the last 12 months

Table 2: Some of the responses about encountered patients, beliefs in treatment, and educational activities on lymphedema among the physiatrists.

	<i>n (%)</i>
In the last 12 months, how many breast cancer-related lymphedema patients have you encountered and/or worked on diagnosis, treatment, or management of lymphedema?	
<10	118 (69%)
10-20	34 (19.9%)
21-30	4 (2.3%)
31-40	3 (1.8%)
41-50	2 (1.2%)
>60	10 (5.8%)
Knowledge about the literature related to predisposing factors of patients suffering breast cancer-related lymphedema	
1 (No prior knowledge)	57 (33.3%)
2	55 (29.2%)
3	44 (25.7%)
4	14 (8.2%)
5 (Detailed knowledge)	26 (3.5%)
For the last 5 years, roughly how many conferences, seminars, practice workshops, or other educational programs on breast cancer-related lymphedema or generally lymphedema have you attended?	
0	74 (43.3%)
1-2	74 (43.3%)
3-5	17 (9.9%)
6-10	3 (1.8%)
>10	3 (1.8%)
Once lymphedema is clinically diagnosed or occurs, eventually, it can be treated	
Fully disagree	19 (11.1%)
Partially disagree	35 (20.5%)
Neither agree nor disagree	24 (14%)
Partially agree	61 (35.7%)
Fully agree	32 (18.7%)
Educational work and raising awareness among health care workers about lymphedema and its genetic and predisposant factors are necessary	
Fully disagree	0
Partially disagree	0
Neither agree nor disagree	2 (1.2%)
Partially agree	7 (4.1%)
Fully agree	162 (94.7%)

The knowledge scores of female and male physiatrists were found to be similar ($P = 0.073$). There was no significant difference in the number of BCRL patients evaluated and treated by female and male physiatrists in the last 12 months ($P = 0.672$, Cramer's $V = 0.072$).

Table 3: Differences in the knowledge score according to demographical characteristics

	Knowledge score mean±SD	<i>P</i>	Effect size
Gender			
Female	16.60±3.77	0.073	0.315 ^a
Male	15.40±3.91		
Years of clinical practice			
<1 year	14.30±3.55	0.556	0.018 ^b
1-5 years	16.54±3.54		
6-10 years	16.46±3.93		
16-20 years	16.20±4.15		
>20 years	16.34±3.91		
Age groups			
20-30	15.78±3.32	0.516	0.014 ^b
31-40	16.77±3.81		
41-50	16.23±4.22		
51-70	15.58±3.66		
Number of patients treated in the last 12 months		<0.001	0.154 ^b
<10	15.57±3.62		
10-20	16.54±3.17		
>20	20.39±3.70		
Location of hospital			
1 st Area - Metropol (ice s (Provinces with Metropolitan Municipalities)	16.46±3.51	0.436	0.010 ^b
2 nd Area - Other Cities	15.52±5.60		
3 rd Area – Districts	15.25±4.34		
Type of hospital			
University Hospital	17.05±3.46	0.333	0.027 ^b
Research Hospital	16.08±4.13		
Other Public Hospitals	16.46±4.11		
Private Hospitals	16.14±4.34		
Private Health Consulting Centers	15.14±3.16		

^aCohen's d, ^bEta-square

Physiatrists who had treated more than 20 BCRL patients had higher knowledge scores than the ones who had treated <20 patients ($P < 0.001$) [Table 3 and Figure 1]. No statistically significant difference in the knowledge scores was observed in regard to the participants' age groups, years of clinical practice, and location and type of hospitals where they are still working [Table 3].

DISCUSSION

Breast cancer-related lymphedema is one of the most common complications seen in breast cancer survivors.^[4,16,18,19] Patients with BCRL seek a specialist for the management of this chronic condition.^[7,14-16]

Physiatrists play an important role in providing information about lymphedema to breast cancer survivors to prevent and manage this complication. BCRL requires lifelong multidisciplinary treatment strategies under the supervision of physiatrists. The physiatrists provide a holistic approach to the problem by integrating not only the physical disabilities but also the psychological, social, and professional dimensions, and the quality of life.^[6,7]

The current study investigated the awareness and knowledge of a group of physiatrists about BCRL. As expected, the BCRL knowledge score was found to be associated with a high number of encountered patients with BCRL. The consultation of BCRL patients with PMR physicians may be important to perceive that PMR specialists need education and further information about differential diagnosis and/or management of BCRL. The knowledge level of physiatrists' did not associate with the period of clinical practice and location of the hospital, indicating the need for continuing education about lymphedema rehabilitation during all times of medical practice both for physiatrists working in metropolises and small cities. Unfortunately, nearly half of the physiatrists did not believe in the treatability of this condition. The most striking results of this study were the lack of detailed knowledge about BCRL treatment among physiatrists and the unmet need for educational activities about BCRL. Therefore, physiatrists should be familiar with the diagnosis, treatment, and follow-up of BCRL to maintain the well-being of these patients.

There are several studies that have indicated a low level of knowledge of lymphedema among patients and clinicians.^[5,8-17] The limited number of previous studies including clinicians has primarily focused on oncologists, surgeons, primary care physicians, and general practitioners.^[14-16] In a study conducted by Paskett and Stark,^[10] it has been reported that physicians do not routinely counsel breast cancer patients on BCRL due to misconceptions about its incidence and prevention strategies. Even when the patients told their clinicians about BCRL symptoms, little concern or action was elicited. The Breast Cancer and Knowledge Study (BC LINK) used an online survey ($N = 887$ of 2,469 invited) of oncologists, primary care physicians, surgeons, and nurse practitioners to assess BCRL knowledge, education, and referral patterns. Oncologists and surgeons scored the highest in all categories, with only 36.2% of primary physicians reporting ever having made referrals for BCRL. This study indicated a need for education about BCRL, especially for primary care physicians but also suggested this education for all specialties. Compared with the primary care

physicians (9.41), oncologists (10.66) had more knowledge followed closely by surgeons (10.40). Furthermore, being female was also associated with higher BCRL knowledge. Civelek *et al.*^[15] investigated the knowledge and attitude of 314 primary care physicians about BCRL with a face-to-face interview method. According to their results, only 37.9% of the participants reported that they had received education about BCRL during their medical faculty and/or residency training. The majority of their study group (64%) had a middle level of self-reported BCRL knowledge, and the knowledge score was found to be related to pre-and postgraduate education about BCRL. No statistically significant difference was observed in BCRL knowledge scores with respect to the gender and years of practice of primary care physicians. To the best of our knowledge, there is no study investigating the awareness and knowledge of physiatrists about lymphedema in the literature. Thus, this is the first study assessing the awareness and knowledge of BCRL among physiatrists.

The limitations of this study should also be addressed. Firstly, the response rate for this online survey was not relatively high for the population of physiatrists in our country, which is nearly 1,500. This low attendance may be related to the low interest in this specific topic, as most physiatrists are specialized in different topics of rehabilitation in recent years. Thus, the results may have limited generalizability. We think that mostly the PMR specialists who are interested and/or who have enhanced with lymphedema patients attended the survey. Additionally, the cross-sectional design of this study may restrain assessing causality between the characteristics of physiatrists, and BCRL awareness/knowledge.

CONCLUSION

We found that physiatrists are moderately aware of BCRL but have limited knowledge of its management and relevant literature. As the incidence of breast cancer and related complications is gradually increasing, there is an urgent need for continuing medical education about BCRL and implementing clinical practice guidelines for physiatrists to prevent lymphedema by educating breast cancer survivors and providing advanced care in the management of this chronic condition. We hope these results offer guidance to the education of physiatrists in regard to risk reduction, diagnosis, treatment, and rehabilitation of patients with BCRL. We suggest intra-disciplinary educational programs including courses, lectures, and clinical practice about BCRL to be incorporated into standard curricula of PMR education.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

REFERENCES

- Carioli G, Malvezzi M, Rodriguez T, Bertuccio P, Negri E, La Vecchia C. Trends and predictions to 2020 in breast cancer mortality in Europe. *Breast* 2017;36:89-95.
- Özmen V, Özmen T, Doğru V. Breast cancer in Turkey; an analysis of 20.000 patients with breast cancer. *Eur J Breast Health* 2019;15:141-6.
- Thomas-MacLean R, Miedema B, Tatemichi SR. Breast cancer-related lymphedema: women's experiences with an underestimated condition. *Can Fam Physician* 2005;51:246-7.
- Keast DH, Despatis M, Allen JO, Brassard A. Chronic oedema/lymphoedema: under-recognised and under-treated. *Int Wound J* 2015;12:328-33.
- Borman P, Yaman A, Yasrebi S, Ozdemir O. The importance of awareness and education in patients with breast cancer-related lymphedema. *J Cancer Educ* 2017;32:629-33.
- Borman P. Lymphedema diagnosis, treatment, and follow-up from the view point of physical medicine and rehabilitation specialists. *Turk J Phys Med Rehab* 2018;64:179-97.
- Fialka-Moser V, Korpan M, Varela E, Ward A, Gutenbrunner C, Casillas JM, *et al.* The role of physical and rehabilitation medicine specialist in lymphedema. *Ann Phys Rehabil Med* 2013;56:396-410.
- Runowicz CD. Lymphedema: patient and provider education: Current status and future trends. *Cancer* 1998;83 (12 Suppl American):2874-6.
- Kwan ML, Shen L, Munneke JR, Tam EK, Partee PN, André M, *et al.* Patient awareness and knowledge of breast cancer-related lymphedema in a large, integrated health care delivery system. *Breast Cancer Res Treat* 2012;135:591-602.
- Paskett ED, Stark N. Lymphedema: Knowledge, treatment, and impact among breast cancer survivors. *Breast J* 2006:373-8.
- Ridner SH. Pretreatment lymphedema education and identified educational resources in breast cancer patients. *Patient Educ Couns* 2006;61:72-9.
- Bosompra K, Ashikaga T, O'Brien PJ, Nelson L, Skelly J, Beatty DJ. Knowledge about preventing and managing lymphedema: A survey of recently diagnosed and treated breast cancer patients. *Patient Educ Couns* 2002;47:155-63.
- Choi JK, Kim HD, Sim YJ, Kim GC, Kim DK, Yu BC, *et al.* A survey of the status of awareness of lymphedema in breast cancer patients in busan-gyeongnam, Korea. *Ann Rehabil Med* 2015;39:609-15.
- Tam EK, Shen L, Munneke JR, Ackerson LM, Partee PN, Somkin CP, *et al.* Clinician awareness and knowledge of breast cancer-related lymphedema in a large, integrated health care delivery setting. *Breast Cancer Res Treat* 2012;131:1029-38.
- Mete Civelek G, Aypak C, Turedi O. Knowledge of primary care physicians about breast-cancer-related lymphedema: Turkish perspective. *J Cancer Educ* 2016;31:687-92.
- 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;9:634-41.
- Sarkar A, Woodman RJ, Zhu C. Clinical awareness and knowledge of breast cancer-related lymphoedema in Australia – an online survey. 5th Conference of International Lymphedema Framework, (oral presentation), 5-7 June 2014, Glasgow, Scotland, UK. Available from: <https://www.lympho.org/2014-glasgow/>.
- Korpan MI, Crevenna R, Fialka-Moser V. Lymphedema: A therapeutic approach in the treatment and rehabilitation of cancer patients. *Am J Phys Med Rehabil* 2011;90:69-75.
- 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;17:1847-53.