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Lymphedema Awareness in Patients Who Underwent Breast Cancer Surgery

Meme Kanseri Cerrahisi Geçiren Hastalarda Lenfödem Farkındalığı

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ABSTRACT Objective: Advances in breast cancer awareness, social attention and imaging have a positive impact on the diagnosis and screening of the disease. The increase in survival rates from breast cancer raises the need for education on patient awareness and lymphedema risk factors. Here, we aimed to analyse the lymphedema awareness in patients who underwent breast cancer surgery in our center. **Material and Methods:** The study was planned prospectively and descriptively. The data were obtained from patients who underwent breast cancer who admitted to the oncology clinic for control via questionnaire. **Results:** Seventy five (n=75) female breast cancer patients between the ages of 34-77 years were included in the study. The mean body mass index (BMI) was 27.6±7.2 kg/m^2. Education levels were: no literacy n=31 (41.3%), primary school graduate n=20 (26.7%), secondary school graduate n=9 (12%), high school graduate n=10 (13.3%), postdoctoral and university n=5 (6.7%). The median duration of the diagnosis of breast cancer was 12 months (minimum: 1 month; maximum: 84 months). The presence of lymphedema in the affected arm was 16% (n=12). Twenty-two of the participants (29.3%) answered yes to the question whether you heard the word lymphedema before. The number of correct answers was median 3 (minimum: 0; maximum: 9). **Conclusion:** It is seen that most of our operated breast cancer patients who participated in the study do not have sufficient knowledge and awareness about the development of lymphedema in the upper extremities and possible complications. We determined that education level is the determinant of knowledge, awareness about lymphedema and possible complications.

Keywords: Breast cancer; lymphedema; rehabilitation; awareness

ÖZET Amaç: Meme kanseri farkındalığı, toplumsal dikkat ve görüntülemedeki gelişmeler hastalığın teşhis ve taramasında olumlu etkisi meme kanserinden sağkalım oranlarının artması hasta farkındalığı ve lenfödem risk faktörleri hakkında eğitim ihtiyacını doğurmaktadır. Burada merkezimizde takipli opere meme kanserli hastalarda lenfödem farkındalığını analiz etmeyi amaçladık. **Gereç ve Yöntemler:** Çalışma prospektif ve tanımlayıcı olarak planlanmıştır. Veriler anketler yoluyla onkoloji kliniğine kontrol için başvuran opere meme kanserli hastalardan elde edilmiştir. Lenfödem ile ilgili bilgiyi ölçen anket ekibimiz tarafından oluşturulmuştur. Cevaplar doğru, yanlış veya bilgim yok şeklinde hazırlanmıştır. **Bulgular:** Çalışmaya 34-77 yaş aralığında 75 opere meme kanserli kadın hasta dâhil edildi. Beden kitle indeksi (BKİ) ortalama 27,6±7,2 kg/m^2 idi. Eğitim düzeyleri: okuma yazma yok n=31 (%41,3), ilkokul mezunu n=20 (%26,7), ortaokul mezunu n=9 (%12), lise mezunu n=10 (%13,3), doktora sonrası ve üniversite n=5 (%6,7) idi. Meme kanseri tanı süresi medyan 12 ay (minimum: 1 ay; maksimum: 84 ay) idi. Etkilenen kolda lenfödem varlığı %16 (n=12) idi. Katılımcıların 22'si (%29,3) "Daha önce lenfödem kelimesini duydunuz mu?" sorusuna evet yanıtını verdi. Doğru cevap sayısı medyan 3 (minimum: 0; maksimum: 9) idi. **Sonuç:** Çalışmaya katılan opere meme kanserli hastalarımızın büyük bölümünün üst ekstremitede lenfödem gelişimi ve olabilecek komplikasyonlar yönünden yeterli bilgi ve farkındalığa sahip olmadığı görülmektedir. Eğitim düzeyinin, lenfödem ve olabilecek komplikasyonlar konusundan bilgi ve farkındalığının belirleyicisi olduğunu tespit ettik.

Anahtar Kelimeler: Meme kanseri; lenfödem; rehabilitasyon; farkındalık

Breast cancer is the most common malignancy and public health problem among women worldwide. In addition to its high incidence, survival rates have increased with the development of early diagnosis and modern treatment methods. The quality of life is affected in subjects associated with impaired body image, relationship with partners and children, treatment side effects, lymphedema, and fear of tumor recurrence after breast cancer treatment.[1] Breast cancer is a life-threatening disease and is one of the leading

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causes of mortality in women (23% of all cancer deaths). Although it is a global health problem, there may be delays in early diagnosis due to the fact that the personal examination and clinical examination of the breasts have not become widespread enough.[2]

Breast cancer patients are not adequately trained by health professionalls about the risk of breast cancer-associated lymphedema and risk reduction strategies. Informing these patients about lymphedema will decrease the risk of developing lymphedema and the progression of the disease.[3] Despite incidence rates, determination of optimal diagnostic tests, effective treatment strategies, and risk reduction guidelines, there are no standardized recommendations for breast cancer-related lymphedema.[4]

Breast cancer awareness, social attentiveness and improvements in imaging have a positive effect on diagnosis and screening. The increase in survival rates from breast cancer raises the need for education on patient awareness and lymphedema risk factors. Despite all these developments, lymphedema develops in one-fifth of women who are treated for breast cancer and causes significant morbidity. Women state that they are not sufficiently informed about lymphedema and other possible side effects after cancer surgery. Today, when breast cancer survival rates are increasing, there is an urgent need for lymphedema awareness and education after surgery. The aim of our study is both to analyze and to raise lymphedema awareness in patients who underwent breast cancer surgery in our center.

MATERIAL AND METHODS

The study was planned prospectively and descriptively. The data were obtained from patients who underwent breast cancer surgery who admitted to the oncology clinic for control via questionnaires. Sociodemographic data of the participants including age, body mass index (BMI), education level, and duration of breast cancer diagnosis were recorded. The questionnaire that measures information about lymphedema was created by our survey team (Table 1). The answers were prepared as true, false, or have no knowledge. The questions left blank were evaluated as "I do not know" category. The presence of lymphedema was determined by measuring the diameter difference in the affected arm. Patients with known cognitive disorder, psychiatric disease, and history of malignancy other than breast cancer were not included in the study.

An approval was obtained from the Kahramanmaraş Sütçü İmam University Faculty of Medicine Clinical Research and Ethics Committee (date: July 17, 2019, no: 04) and the Helsinki Declaration principles were followed in the study. Informed consent form was taken from the participants.

TABLE 1: Distribution data of answers.

Questions (Q):	Right n/%	False n/%	No idea n/%	Number of correct answer n/%
Q1: The swelling that develops over time in the effected arm is called lymphedema.	25/33.3	0	50/66.7	25/33.3
Q2: Lymphedema may develop soon after surgery or years later.	27/36	5/6.7	43/57.3	27/36
Q3: I should not wear accessories such as watches, rings or bracelets on the effected arm.	35/46.7	4/5.3	36/48	35/46.7
Q4: I should not use smelling or skin irritating creams on the effected arm.	42/56	0	33/44	42/56
Q5: I should protect my arm from infections and traumas.	43/57.3	0	32/42.7	43/57.3
Q6: Loss of strength, pain, numbness and limitation of movement may develop in my effected arm.	44/58.7	2/2.7	29/38.7	44/58.7
Q7: There is no cure for lymphedema.	8/10.7	5/6.7	51/68	8/10.7
Q8: In the treatment of lymphedema, physical therapy, physical activity, massage, acupuncture, healing touch, hypnosis, music therapy, yoga, thai chi, behavior therapy are performed.	15/20	2/2.7	47/62.7	15/20
Q9: March 6 is the world day of lymphedema awareness.	7/9.3	1/1.3	56/74.7	7/9.3

STATISTICAL ANALYSIS

All statistical analyzes were carried out by using IBM SPSS version 19 (IBM Corp., Armonk, NY, USA). Categorical variables were given as percentage, continuous variables as mean and standard deviation. The answers given to the questionnaire were divided into 3 categories as true, false, or have no knowledge, and were given as numerical and percentage. The correct number of answers was given median. Normal distribution was evaluated by Kolmogorov-Smirnov test. We used binary logistic regression analysis statistical method to examine the relationship between lymphedema presence and demographic parameters as dependent variable, lymphedema presence is categorical. The relationship between demographic data and questionnaire questions were evaluated with Mann-Whitney U test. Spearman test was used for correlation analysis. A p value of <0.05 was considered statistically significant.

UPPER EXTREMITY DIAMETER MEASUREMENTS

Lymphedema of the upper extremity was evaluated with the circumferential method. The circumferential upper extremity measurements were performed with the arm abducted at 30°, starting at the level of the carpometacarpal joint, every 5 cm proximal to this point along both extremity. Interextremity volume difference was defined as edema.[5]

PREPARATION OF THE SURVEY

In the literature, there was no standardized questionnaire regarding the awareness of breast cancer and lymphedema. The questionnaire was prepared by a physiatrist and a clinical oncologist considering general literature information, risk factors and complications in the current data. Before taking patients into the study, we tested whether the questionnaire we prepared was understandable in 3 of our patients.

RESULTS

Seventy-five (n=75) female breast cancer patients between the ages of 34-77 were included in the study. The mean BMI was 27.6±7.2 kg/m^2. Education levels were; literate n=31 (41.3%), primary school graduate n=20 (26.7%), secondary school graduate n=9 (12%), high school graduate n=10 (13.3%), post-doctorate and university n=5 (6.7%). Median breast cancer diagnosis period was 12 months (minimum: 1 month; maximum: 84 months).

The presence of lymphedema in the affected arm was 16% (n=12). Twenty-two of the participants (29.3%) answered yes to the question whether you heard the word lymphedema before. For those who said yes to this question, source of 3 (4.0%) was from television, 1 (1.3%) was from social media, 6 (8%) was from friends, 9 (12%) was from health professional, 19 (25.3%) marked except those. The correct number of answers was median 3 (minimum: 0; maximum: 9). The distribution of responses to all questions is summarized in Table 1.

In binary logistic regression analysis model, education level (p=0.029) and BMI (p=0.008) were found to be significant in determining the presence of lymphedema (Table 2). In the correlation analysis, the number of correct answers were positively correlated with the educational status (rho=0.382; p=0.002) (Table 3) (Figure 1). The number of correct answer was not correlated with age, BMI and disease duration. The number of correct answer was similar in the group with or without lymphedema (p=0.524) (Figure 2).

TABLE 2: Binary logistic regression analysis model.

	β	p value
Age	-0.84	0.073
Education level	-1.091	0.029*
Duration of disease	0.017	0.546
BMI	-0.331	0.008*

Dependent variable: lympedema presence; *p<0.05; BMI: Body mass index.

TABLE 3: Correlation analysis between number of right answers and sociodemographic data.

Number of right answers→	Rho	p value
Age (year)	-0.187	0.139
Education level	0.382	0.002*
Duration of disease (months)	-0.076	0.558
BMI (kg/m^2)	0.088	0.492

*p<0.05, statistically significant; BMI: Body mass index.

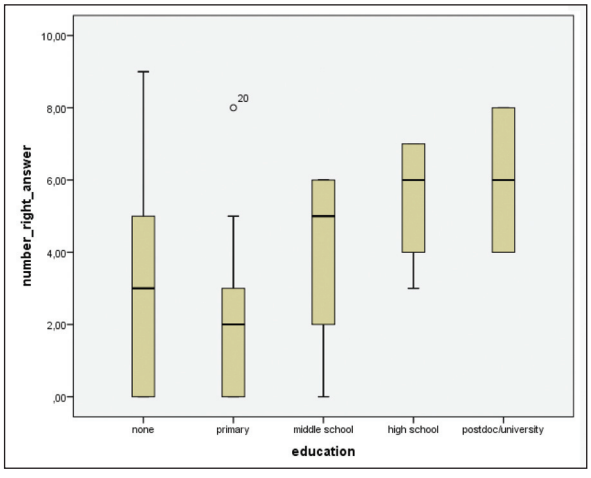

FIGURE 1: Graphic of number of right answers and education level.

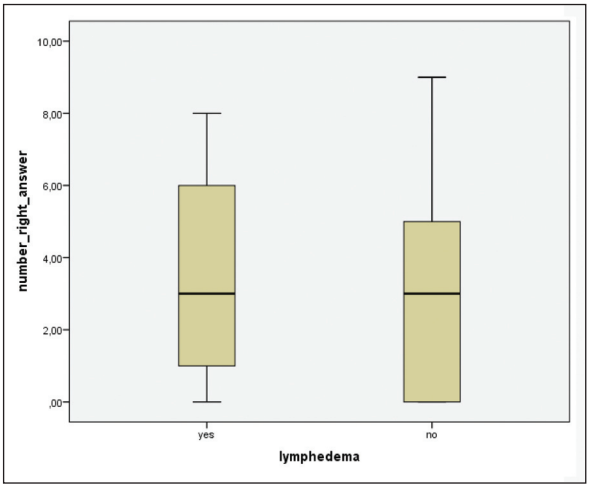

FIGURE 2: Graphic of number of right answers and lymphedema presence.

DISCUSSION

Breast cancer is the most common type of cancer among women worldwide and upper extremity lymphedema is one of the most annoying complications of treatment.[6-8] Lymphedema is a late-stage effect of treatment seen in 3-60% of patients with breast cancer. The affected side is characterized by swelling of the hands, arms and/or breasts, pain, redness, limited hand and arm movements, and stiffness. These symptoms not only restrict physical function, but also affect quality of life, body image, social function and financial status. Unfortunately, there are no standardized methods for breast cancer-related lymphedema prevention, diagnosis and treatment. Besides its prevalence, clinical guidelines and trials are inadequate, its underlying mechanism is poorly understood.[9]

Risk factors such as mastectomy, axillary lymph node dissection or radiation therapy cannot be avoided in the development of lymphedema associated with breast cancer. In addition, risks such as upper extremity minor infections, injury, trauma, excessive use of the extremity, and air travel can be modified.[10]

Lymphedema can negatively affect quality of life. Although advances in breast cancer treatment reduce the risk of lymphedema, its effect on patients remains the same. Lymphedema development causes dysfunction in the affected arm, decrease in strength, physical disorders including fatigue and pain. Anxiety, frustration, sadness, irritability, fear are also observed in the affected women with decreased self-confidence due to impaired body image. Breast cancer-related lymphedema treatment should aim to provide physical, psychosocial and emotional well-being.[11]

Although breast cancer-related lymphedema treatment is completed, it may present with pain and disability affecting daily and business life years later. The risk is higher especially in patients receiving radiation therapy and axillary lymph node dissection.[12] In our study, lymphedema presence was 16% compatible with the literature and we found that education level and BMI are the predictors of lympedema presence.

Few data related to awareness were found in the literature. Kwan et al. in their study, received information via telephone and the mean lymphedema awareness score was 4 (0-7). They found a higher rate of lymphedema awareness in individuals under 50 years of age and higher education level.[3]

Pyszel et al. observed more disability, lower quality of life, increased psychosocial stress in women who developed lymphedema due to breast cancer.[13] Altintas et al. showed that cancer fatalism and health beliefs were affected by breast cancer awareness.[14] Borman et al. observed that in the study on lymphedema awareness, 19.5% of the participants

received information and education about lymphedema and 80.5% did not have knowledge, and the results were not correlated with the level of education and lymphedema.[15] In our study, only 33.3% of breast cancer patients knew the definition of lymphedema; in the group with or without lymphedema, it was observed that the number of correct answers was similar, and that there was a positive correlation with the level of education. It was found that half of the participants were informed about the precautions they should take to prevent the development of lymphedema. We also observed that the presence of lymphedema had no effect on patient's awareness. Lymphedema patients would be expected to have more information about lymphedema. The median duration of diagnosis was 1 year in patients participating in the study, which supports that the participants are mostly composed of newly diagnosed patients. During this period, the primary illnesses of the patients are mostly focused and not sufficiently informed about possible complications such as lymphedema.

In his study, Fu et al. observed less symptoms (swelling, feeling of heaviness, impaired shoulder mobility, seroma, swelling of the breast) in individuals after patient information in lymphedema associated with breast cancer.[10] Awareness of lymphedema increase after the training. Similar results were observed in the study by Thomas-MacLean et al.[12]

Lymphedema treatment has been improving in recent years. Physical therapy modalities such as self-massage, manual lymphatic drainage, therapeutic physical exercises, compression bandage, elastic compression garments, kinesio tape, pneumatic compression, ultrasonic, electrostatic, extracorporeal shock wave therapy, electrical muscle stimulation and laser therapy are used in the treatment of post-mastectomy lymphedema.[15,16] Choi et al. observed that the vast majority of Korean breast cancer patients had low breast cancer related lymphedema awareness or misinformation and were not sufficiently informed about lymphedema.[16] As can be seen, studies in different countries show that patients do not have enough information about lymphedema risk factors and complications.[17] Informing patients about breast cancer will prevent possible complications.

Little is known about lymphatic changes in the arm during surgery and the onset of edema.[18-22] Women with higher lymph flow than axilla are thought to have a higher risk of developing lymphedema.[23] According to the metaanalysis by Fodor, the following factors have to be considered for decisions regarding dissection or irradiation: patient wishes, general condition, age, the necessity of pathological nodal status for systemic therapy and the risk of post-treatment morbidity. Patient should be fully informed about the benefits and the potential side effects of treatments.[23-25] Lymphedema patients should be informed about standard therapies applied and new emerging methods.

It was observed that 20% of the patients answered correctly to the 8th question (Q8) that asked about the treatment of lymphedema. World Lymphedema Day is an annual advocate-driven celebration, which was established in 2016 by the United States Senate in response to a bill written by the Lymphatic Education & Research Network. The goal is to make cures for lymphedema and lymphatic diseases a global priority. Various events are organized in our country by various associations and organizations on March 6 to increase awareness of lymphedema. Only 9.3% of the participants (Q9) stated that they have information about this day.

The limitations of the study were question 8th and 9th may be relatively difficult for such a literate or primary school education group. Also we do not have any information on how much this group uses social media tools such as television, newspapers and the internet. The number of patients (n=3) in our pretest is not sufficient.

CONCLUSION

Few of the patients with breast cancer have sufficient knowledge and awareness on this subject. Up to half of patients are informed about possible complications. Education level is the determinant of lymphedema awareness.

Especially breast cancer patients should be followed closely for possible lymphedema development. Early and continuous education in breast cancer cases is the cornerstone of future treatment management. Therefore, educational program net-

works including age, disease duration and lymphedema treatment should be developed. Surgery targets should be among the treatment targets for the development of new techniques, to define risk factors well, and to increase the education and awareness of patients in terms of possible complications, especially lymphedema.

Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

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