Lymphedema Information and Prevention Practices of Women After Breast Cancer Surgery

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Abstract

AIM: This study was carried out to determine women’s knowledge about lymphedema precautions and their practice status. The sample of this descriptive and correlationally designed study included 107 women who underwent surgery.

METHOD: This descriptive study’s data were collected using a questionnaire form developed by the researcher. The data were structured on a 3-point Likert-type scale. The one-way analysis of variance, correlations, and the Kolmogorov–Smirnov test were used in the statistical analysis.

RESULTS: Three-quarters of the women knew that they should do arm exercises, keep the arm above the heart level while resting, and that blood pressure should not be measured, and jewelry not be worn. However, it was found that the percentage of women who did not know that the arm circumference should be measured at regular intervals or how to evaluate the arm circumference measurements and what to do in case of an injury was the same. It was determined that the precautions that the majority of women took in measuring lymphedema consisted of not measuring blood pressure, not wearing tight jewelry, and wearing an appropriate bra.

CONCLUSION: It is thought that patients should be informed about the development of lymphedema after breast cancer surgery because their compliance with taking the precautions will be important in reducing the incidence, degree, and effects of lymphedema.

Keywords: Breast cancer, lymphoedema, mastectomy, nursing

Introduction

Breast cancer is the most common cancer among women globally; and in fact, 1.1 million new cases of breast cancer are reported yearly. Around the globe, 23% of all the cancers seen in women are breast cancer (Özmen, 2014), and these rank 5th among the causes of death associated with cancer in women (Globocan, 2012). In Turkey, breast cancer is the most common (43.0/100,000) type of cancer (Şencan & Keskinkılıç, 2017).

Breast conservation surgery and modified radical mastectomy are widely used in the surgical treatment of breast cancer in Turkey. Surgical treatment prolongs the lifespan but causes some problems that negatively affect the quality of life of the patient (Bhatt et al., 2016; Gürsoy et al., 2006; McNeely et al., 2016). These problems include pain, lymphedema, impaired body image, anxiety, decreased self-esteem, depression, anger, decreased libido, and changes in family and work life (Babacan-Gümüş, 2006; Gürsoy et al., 2006; Sturgeon et al., 2017). One of the problems the patient faces after axillary dissection is lymphedema, which is a significant issue because it has a negative effect on the quality of life and improvement after surgery (Gürsoy et al., 2006; Lee et al., 2018; Özaslan & Kuru, 2004). It has been found in studies that women develop lymphedema in their 3rd year after breast cancer surgery at a rate of 17.5%–49.1% (Demir, 2008; Sackey et al., 2014; Sackey et al., 2015; Sherman et al., 2017).

Lymphedema due to breast cancer surgery causes functional disability in the arm on the operated side, weakness, failure to fulfill daily activities and roles within the family, deterioration in body image, and decreased quality of life and self-esteem (Gürsoy et al., 2006; Lee et al., 2018). Functional disability caused by lymphedema restricts arm movements, reduces the healing capacity of the affected tissue, increases the risk of infection, and leads to pain in
the patient (Gümüş, 2006; Ozaslan & Kuru, 2004). It has been reported that such lymphedema-related problems are severe in 1 of 4 patients undergoing breast cancer surgery (Norman et al., 2001).

Lymphedema can be prevented by appropriate nursing interventions after breast cancer surgery. It has been determined in studies that most participating women were not aware of lymphedema before its development, did not notice the symptoms, and did not carry out any preventive practice (Gümüş, 2006; Gürsoy et al., 2006). It is, therefore, important in terms of reducing the impact of lymphedema on the quality of life of patients undergoing breast cancer surgery to provide them with planned training. The main responsibility of the nurse in this context is to ensure that the patients are discharged with adequate information (Ridner, 2005; Thomas-MacLean et al., 2005).

The studies conducted in our country on lymphedema are mostly related to the incidence, prevalence, risk factors, and treatment options of the condition. Although there are several studies examining the lymphedema-related health problems among women, no study could be found that determined the levels of knowledge about lymphedema. This study, thus, aimed to determine what lymphedema precautions were being taken and the patients’ status of practicing these precautions after breast cancer surgery.

**Research Questions**
1. What are the women’s knowledge and practices measures to prevent lymphedema?

2. What are the status and reporting of women about lymphedema measures?

3. What are the measures to prevent infection in women’s surgical procedures?

4. What are the affecting intrinsic features in women’s lymphedema prevention information and application score?

**Method**

**Study Type**
The study was conducted using the one group, descriptive and correlational design.

**Sample**
Inclusion criteria was defined as patients who were over 18 years old, cognitively intact, able to perform activities of daily living (before surgery), had undergone breast cancer surgery for the first time, and had axillary dissection. Patients with other health problems (such as amputation and filariasis), a psychiatric diagnosis, and visual, hearing, or speech disabilities were excluded from the study (October 2017-October 2018).

The sample of the study consisted of patients who underwent breast cancer surgery in the past 5 years at a hospital in a city in the Eastern Black Sea region. All the patients who had undergone surgery during this period were contacted; 9 of 112 patients were not interviewed because of lack of contact information. Because of the older ages of 4 patients, the inability of 2 patients to perform daily activities alone, and 3 patients who had different problems, the study was completed with 103 patients.

**Data Collection**
Using the hospital surgical records, the patients were contacted by phone, informed of the study, and their oral informed consent was obtained. The data were gathered using a three-part questionnaire developed by the researchers. The first part included 17 questions about the patients’ demographic characteristics, surgery process, and information about the post-surgery period. The second part had 20 questions on the women’s knowledge about lymphedema precautions. The third part, consisting of a form of 22 Likert-type questions, determined the women’s status of practicing lymphedema precautions. The third part, consisting of a form of 22 Likert-type questions, determined the women’s status of practicing lymphedema precautions. This part was scored on the basis of 3 different points ranging from 0 to 2, with 2 points defined as knowing and applying, 1 point as partly knowing and applying, and 0 as not knowing or applying. The scores obtained from each prevention were added, and the total knowledge and practice scores were calculated. According to the scoring system, the lowest possible score was 0, and the highest score was 45. Before using the questionnaire forms, the expert opinions of 5 surgical nurses and 5 academicians were enlisted, and the necessary corrections were made on the basis of their recommendations. After the questionnaire forms were finalized, the pre-test phase was conducted with 10 patients, and the study was initiated after the questions were revised once again. In this study, Cronbach’s alpha reliability coefficient (α) on knowledge and practice was found to be 0.915.

**Statistical Analysis**
The study data were processed using the Statistical Package for Social Sciences 21.0 (IBM SPSS Corp.;
Armonk, NY, USA) package program. Data assessment was conducted using percentages, the Mann–Whitney U test, Kruskal–Wallis test, one-way analysis of variance, correlation analysis, the t test, and the Kolmogorov–Smirnov test to determine whether the data followed a normal distribution. Results were considered significant at p<0.05; the confidence interval was set at 95%.

Ethical Considerations
Before the implementation of the study, the ethics committee approval and written permission from the hospital were obtained from the Karadeniz Technical University Faculty of Medicine Clinical Research Ethics Committee on January 13, 2015 (No. 26). In collecting the data, the researcher informed the patients about the purpose, method, and scope of the scientific research, and their consent was obtained via informed consent.

Results
The average age of the study participants was 54.0±12.3 (min: 28, max: 86) years. Of the participants, 78.6% were housewives, 80.6% had a modified radical mastectomy, and 53.4% had chemotherapy and radiotherapy treatment in addition to the surgery. The participants were interviewed at 3±1.5 (min: 0.4, max: 5) years after the surgery. After the surgery, 57.3% of the participants had edema on the arm, and 58.3% of the participants with edema had the condition in the upper part of the elbow. Of those with edema, 36.7% reported mild-grade edema, and 58.3% were treated for edema. Of the participants (52.4%) who stated that they had knowledge about lymphedema, 66.7% had received information from the physicians at the time they were discharged, and 64.8% received education in the postoperative period. It was found that 83.3% of the participants preferred oral narration in their training, and only 1.9% were given booklets/brochures.

It was determined that 84.4% of the participants knew that measuring blood pressure was not a preventive measure for lymphedema, 71.8% knew that arm exercises should be performed, and 67.9%
knew that the arms should be kept above the heart level while resting and that tight jewelry should not be worn (Table 1). However, it was found that 80.5% of the participants did not know how to evaluate the arm circumference measurements, 75.7% did not know that arm circumference should be measured at regular intervals, and 59.2% did not know what to do in case of an injury (Table 2).

Women who stated that they knew or partially knew about lymphedema measures were asked about their use of this prevention (Table 3). It was found that 86.6% of the participants who knew or partially knew about the precautions were aware that blood pressure should not be measured from the arm, 80.7% did not wear tight jewelry, and 78.4% did not use an underwire bra. In contrast, 73.5% of the participants did not perform arm exercises regularly, 44% did not measure the arm circumference, and 41.6% did not engage in walking, swimming, or aerobics; 50% of the participants knew the symptoms of edema, and 46.1% knew of the symptoms of pain, redness, and temperature (Figure 1).

It was found that half of the participants knew that the hand and arm on the operated side should be protected from parenteral procedures (64.5%), microorganisms (55.3%), and burns (50%); less than half of the participants knew about other preven-

| Measures                              | Applying | Partly applying | Not applying |
|---------------------------------------|----------|-----------------|--------------|
| Measuring blood pressure              | 90 (87.3)| 78 (86.6)       | 3 (3.3)      | 9 (10.1)    |
| Arm exercises                         | 83 (80.5)| 67 (80.7)       | 5 (6.1)      | 11 (13.2)   |
| Keeping the arm above heart level while resting | 82 (79.6)| 60 (73.2)       | 8 (9.7)      | 14 (17.1)   |
| Jewelry not to be tight               | 79 (76.6)| 58 (73.5)       | 14 (17.7)    | 7 (8.8)     |
| Weight within normal limits           | 75 (72.8)| 47 (62.6)       | 19 (25.3)    | 9 (12.1)    |
| Walking, swimming, aerobics           | 74 (71.8)| 58 (78.4)       | 7 (9.5)      | 9 (12.1)    |
| Protection of the arm from trauma (sunburn) | 73 (70.8)| 35 (47.9)       | 23 (31.5)    | 15 (20.5)   |
| Do not wear a tight bra               | 72 (69.9)| 25 (34.7)       | 17 (23.6)    | 30 (41.6)   |
| No direct application of heat to arm  | 70 (67.9)| 42 (60.0)       | 16 (22.8)    | 12 (17.1)   |
| Not to use an underwire bra           | 61 (59.2)| 39 (64.0)       | 10 (16.4)    | 12 (19.6)   |
| Avoidance of heat (bath etc.)         | 57 (55.3)| 38 (66.7)       | 13 (22.8)    | 6 (10.5)    |
| Heavy breast prosthesis not to be used| 55 (53.3)| 36 (65.4)       | 11 (20.1)    | 8 (14.5)    |
| Things to do in case of injury        | 43 (41.7)| 28 (65.1)       | 6 (14.0)     | 9 (20.9)    |
| Measuring arm circumference at regular intervals | 25 (24.2)| 8 (32.0)        | 6 (24.0)     | 11 (44.0)   |
| Evaluation of arm circumference measurements | 20 (19.4)| 5 (25.0)        | 9 (45.0)     | 6 (30.0)    |
It was found that the mean score for knowledge of lymphedema was 16.0±7.5 (min: 0, max: 30), and the mean practice score was 13.7±7.7 (min: 0, max: 30). There was a significant difference between the lymphedema data of the patients according to their educational status (p=0.001). It was found that the working status and history of edema were the significant variables affecting knowledge (p=0.01, p=0.03) and practice (p=0.02, p=0.02). The type of surgery was not significant in terms of knowledge (p>0.05) but was found to be significant in terms of practice status (p=0.001). There was no statistical difference between the women in terms of knowledge level and practice status (p>0.05) according to other independent variables (Table 4). In addition, a significant correlation was found between the participants’ knowledge scores and status of their preventive lymphedema practices (r=0.68, p<0.0001).

**Discussion**

One of the problems adversely affecting the quality of life of patients after the surgical treatment of breast cancer is lymphedema. Lymphedema is a difficult health problem to treat once it develops. In this context, self-care education plays an effective role in preventing this health problem. Patients who are discharged with insufficient information postoperatively fail to cope with the problems associated with lymphedema (Gül & Erdim, 2009).

It was determined in the study that half of the patients received training about lymphedema upon their discharge from the hospital. In other studies, it has been stated that women did not receive information before lymphedema developed and also did not know the symptoms of the condition. Women receiving information obtained it from physiotherapists, books, and oncology staff (Bosompra et al., 2002; Cho, 2004; Lee et al., 2018; Paskett & Stark, 2000). It was found that half of the patients knew about swelling, and less than half knew about the symptoms of temperature, pain, and redness. In the qualitative study of Muezzinler and Karayurt (2014), it was observed that the patients were only aware of the signs of pain, redness, and swelling. When the results of different types of studies are examined, it can be seen that women received information about lymphedema at different times, the desired level of knowledge about lymphedema was not reached, and they were unable to observe the symptoms (McPherson, 2016).

It was found that three-quarters of the participants knew about the precautions of avoiding measuring the blood pressure from the affected arm, exercising, keeping the arm at the heart level, and not wearing tight jewelry. The least known measures

| Measures                                                                 | Knowing n (%) | Not knowing n (%) |
|-------------------------------------------------------------------------|---------------|-------------------|
| Protect the side of the operated side from parenteral procedures        | 59 (57.3)     | 44 (42.7)         |
| Protect the hands and arms from the side of the operation from microorganisms | 52 (50.5)     | 51 (49.5)         |
| Protect hands and arms from burns on the side of surgery                | 48 (46.6)     | 55 (53.4)         |
| Do not perform a manicure on the operated side                          | 45 (43.7)     | 58 (56.3)         |
| Protect the arm on the operated side from animal bites and injury        | 43 (41.7)     | 60 (58.3)         |
| Using gloves when in contact with soil                                  | 42 (40.8)     | 61 (59.2)         |
| Do not use a razor blade in the hair cleaning                            | 38 (36.9)     | 65 (63.1)         |
| Using gloves when there is a risk of interruption                       | 37 (35.9)     | 66 (64.1)         |
| Protect your arm from sun rays                                          | 35 (34.0)     | 68 (66.0)         |
| Close the wound with sterile gauze after the any injury                 | 35 (34.0)     | 68 (66.0)         |
| To use a thimble on the finger when sewing                              | 32 (31.1)     | 71 (68.9)         |

It was found that the mean score for knowledge of lymphedema was 16.0±7.5 (min: 0, max: 30), and the mean practice score was 13.7±7.7 (min: 0, max: 30). There was a significant difference between the lymphedema data of the patients according to their educational status (p=0.001). It was found that the working status and history of edema were the significant variables affecting knowledge (p=0.01, p=0.03) and practice (p=0.02, p=0.02). The type of surgery was not significant in terms of knowledge (p>0.05) but was found to be significant in terms of practice status (p=0.001). There was no statistical difference between the women in terms of knowledge level and practice status (p>0.05) according to other independent variables (Table 4). In addition, a significant correlation was found between the participants’ knowledge scores and status of their preventive lymphedema practices (r=0.68, p<0.0001).
| Variables                                  | n   | %    | Knowledge X±SD | Practice X±SD |
|-------------------------------------------|-----|------|----------------|---------------|
| **Age**                                   |     |      |                |               |
| 28–44                                     | 29  | 28.2 | 15.0±7.4       | 13.6±6.8      |
| 45–52                                     | 29  | 28.2 | 17.4±6.9       | 14.3±8.8      |
| 53–60                                     | 25  | 24.3 | 13.4±7.6       | 11.1±6.4      |
| 61–86                                     | 20  | 19.4 | 19.0±7.4       | 16.4±8.4      |
|                                            |     |      |                |               |
| **Education status**                      |     |      |                |               |
| Illiterate                                | 28  | 27.2 | 11.7±6.0       | 11.9±7.0      |
| Literate-Primary                          | 45  | 43.7 | 17.3±7.8       | 15.4±7.2      |
| Secondary school and over                 | 30  | 29.1 | 18.2±6.9       | 12.9±8.7      |
|                                            |     |      |                |               |
| **Working status**                        |     |      |                |               |
| Working                                   | 14  | 13.5 | 19.8±6.6       | 17.1±6.6      |
| Not working                               | 89  | 86.5 | 15.1±7.4       | 12.9±7.4      |
|                                            |     |      |                |               |
| **Postoperative treatment status**        |     |      |                |               |
| Chemotherapy                              | 47  | 45.6 | 14.5±7.6       | 13.8±7.8      |
| Chemotherapy and Radiotherapy             | 56  | 54.4 | 17.3±7.3       | 13.6±7.7      |
|                                            |     |      |                |               |
| **Type of surgery**                       |     |      |                |               |
| Breast preservation+axillary dissection   | 20  | 19.4 | 16.0±7.4       | 8.7±9.3       |
| Modified radical mastectomy               | 83  | 80.5 | 16.1±7.6       | 14.9±6.8      |
|                                            |     |      |                |               |
| **Edema**                                 |     |      |                |               |
| Yes                                       | 61  | 59.2 | 17.4±7.6       | 14.7±8.2      |
| No                                        | 42  | 40.8 | 14.1±7.1       | 12.3±6.9      |
|                                            |     |      |                |               |
| **Edema grade**                           |     |      |                |               |
| Light <3cm                                | 32  | 53.3 | 17.0±7.3       | 14.3±8.8      |
| Medium 3–5 cm                             | 17  | 28.3 | 15.4±6.9       | 14.0±6.4      |
| Severe >5cm                               | 11  | 18.4 | 20.5±8.67      | 16.0±8.4      |

F=2.61, p=0.05
F=1.83, p=0.14
F=7.41, p=0.001
F=1.97, p=0.14
F=2.60, p=0.01
F=2.27, p=0.02
F=1.86, p=0.06
F=0.1, p=0.92
F=0.05, p=0.95
F=3.41, p=0.001
F=2.18, p=0.03
F=2.22, p=0.02
F=2.16, p=0.09
F=0.62, p=0.60

F=1.83, p=0.14
were the need to evaluate the arm circumference measurements, the need to regularly measure the arm circumferences, and what to do in case of an injury. It has been observed that patients are generally informed about invasive procedures, blood pressure measurement, injections, blood draws, arm exercises, and avoiding trauma (Gül & Erdim, 2009). In the study of Sherman et al. (2015), it was asserted that women experiencing lymphedema were more diligent about performing exercises, and that they knew about how blood pressure should not be measured from or injections made into the affected arm (Sherman et al., 2015). In addition, a systematic analysis shows that when women fail to exercise, their quality of life and physical functions suffer, and their complaints of nausea and vomiting increase (McNeely et al., 2006). In a randomized controlled study, it was observed that women who did weight-lifting exercises were successful in preventing lymphedema (Schmitz et al., 2010). Study suggest that exercise is an important factor in preventing lymphedema.

Approximately three-quarters of the women stated that they did not measure blood pressure from the affected arm, did not wear tight jewelry, wore an appropriate bra, and exercised. The least applied measures were measuring and evaluating the arm circumferences and engaging in sports. It is generally seen that women implement the measures that they have knowledge about. In one study, 91.7% of the patients did not measure blood pressure from the affected arm (Ferguson et al., 2016). In a study examining the causes of lymphedema development, measuring the blood pressure was defined as a significant risk that increased the incidence of lymphedema (Meeske et al., 2009). The fact that women know about not having measurements taken from the arm and that this practice significantly increases the rate of lymphedema indicates that the information had been repeated in the training.

In the context of precautions to be taken to prevent an infection in the arm, approximately half of the women knew how to protect the arm from parenteral interventions, microorganisms, and burns. The results show that women have insufficient knowledge about this issue. In one study, the rate of women not receiving injections was noted as 95.3% (Ferguson et al., 2016). Despite the fact that women are reminded at each invasive procedure that they should not have an injection, the low rate of implementation of this practice in Turkey suggests that the expected learning has not taken place.

It was found that the knowledge of women with secondary or higher education was at a higher level than among the others. As the level of education increases, the awareness of the need for information and the search for knowledge increases. It is, therefore, expected that individuals at higher education levels will be more knowledgeable. The working status of a woman along with a history of edema is a significant variable affecting both knowledge and practice. The higher levels of education among working women may be responsible for the increased knowledge. Women may also encounter more information in their work environment. This may be explained by the fact that women with edema are in search of information or have been more informed in the treatment process. It is also expected that women who have knowledge are more ready to engage in preventive practices. In addition, among women who had undergone mastectomy, the percentage of those who stated that they had implemented the precautions was significantly higher than among those who had undergone breast conservation surgery. In one study, women’s education levels were seen to be effective in their implementing lymphedema measures (Hanna et al., 2017). In another study, it has been shown that women’s having knowledge of lymphedema measures significantly contributes to lymphedema management (Sherman et al., 2015). In the study by Ridner et al., it was pointed out that the training that women receive from the health professionals related to lymphedema measures is inadequate and that when education levels increase, there is also an increase in women’s implementation behavior regarding these measures (Ridner et al., 2011). According to this information, it can be said that a woman’s education level affects information-seeking behaviors, creating differences in the application of lymphedema management in cases of breast cancer.

Study Limitations
First, it contains only the results obtained at the hospital from the patients who agreed to participate. Second, because there is no scale validated for the Turkish language that can be used to determine the knowledge and applications regarding lymphedema prevention, the needed data were obtained with a Likert-type questionnaire that was developed by the researcher.
Conclusion and Recommendations

The results of the study show that women do not have knowledge about lymphedema and that the knowledge is effective in applying lymphedema measures. Following the surgical treatment, patients need to gain enough knowledge about lymphedema before discharge, which will help prevent any problems in the post-treatment period. The nurse should discharge the patients after they are individually equipped with the planned education, and the patients should be monitored at the time of hospital admission and at home. Furthermore, new training methods can be developed for use in addition to the widely adopted oral training. Care must be taken to ensure that the new training methods to be determined will provide information and encourage behavioral change.

Ethics Committee Approval: This study was approved by Ethics committee of Karadeniz Technical University Faculty of Medicine Clinical Research Ethics Committee (Approval No: 2015/ 26).

Informed Consent: Verbal informed consent was obtained from the patients who agreed to take part in the study.

Peer-review: Externally peer-reviewed.

Author Contributions: Supervision - A.A., A.G.; Design - A.A., A.G.; Supervision - A.A., A.G.; Resources - A.A., A.G.; Materials - A.A., A.G.; Data Collection - A.A., A.G.; Analysis - A.A., A.G.; Literature Search - A.A., A.G.; Writing Manuscript - A.A., A.G.; Critical Review - A.A., A.G.

Conflict of Interest: The authors have no conflict of interest to declare.

Financial Disclosure: The authors declared that this study has received no financial support.

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