J Canc Educ (2017) 32:432–437
DOI 10.1007/s13187-015-0965-2

The Information Needs of Women Who Have Undergone Breast Cancer Surgery in the West of Turkey

Ummu Yildiz Findik[1]

Abstract This descriptive study aimed to evaluate the information needs of breast cancer patients who have undergone surgery, and the level to which those information needs are met in the west of Turkey. It was conducted in 55 women who had undergone surgical intervention between March 2013 and March 2014 in a university hospital in the west of Turkey. A personal information form and the Patient Information Needs Scale were used to gather data. Descriptive statistics, the Chi-square test, and the Wilcoxon signed-rank test were used to analyze the data. It was found that the information need of the patients (3.9 +/− 0.6) was near the "very important" level, and that this need was "somewhat met" (2.4 +/− 0.9). When the information needs of the patients and the level to which those needs were fulfilled were compared, the level of fulfillment was statistically significantly lower ($p < 0.001$). Among the different subscales evaluated, information relating to medication was the most needed, and the information needs pertaining to this subscale were met to a greater degree ($p < 0.05$) than the remaining subscales. The results showed that the information needs, primarily the medication-related information needs, of the patients were high, but that the level of meeting these needs was low. It should be considered important for patients who have undergone breast cancer surgery to be kept informed and provided with information regarding their medication.

Keywords Breast cancer · Surgery · Patient information need · Nurses

---

✉ Ummu Yildiz Findik
ummuyildiz@trakya.edu.tr

[1] Faculty of Health Sciences, Department of Nursing, Trakya University, 22030 Edirne, Turkey

Introduction

Breast cancer is the most frequently diagnosed cancer and the leading cause of cancer death in females worldwide, accounting for 23 % (1.38 million) of total new cancer cases and 14 % (458,400) of total cancer deaths in 2008 [1]. It has been estimated that over 508,000 women worldwide died as a result of breast cancer in 2011 [2]. In Turkey, among the most widely seen cancers (e.g., thyroid 8.5 %, colorectal 7.9 %) in women of all age groups in 2009, the rate of breast cancer was 23.4 % [3]. And Ministry of Health data predicted 51,990 cases of breast cancer in Turkey in 2012 (Özmen, 2008).

Effects of Breast Cancer

Breast cancer is a significant cause of trauma for patients and their families, as a result of the diagnosis, surgical intervention, the psychosocial difficulties that may occur as a consequence of the loss of a breast, post operational treatment, and other related problems [4]. Surgery is often required to remove a breast tumor, and, following this surgery, women may experience anger, fear, disappointment, loss of control, low self-esteem, a change in body image, sexual problems, fear of losing their womanhood, concern regarding a relapse of the disease, difficulties finding appropriate clothing, problems related to breast implants, and mortality issues [5]. Cechini [6] found that 31 % of patients reported that their daily activities (e.g., housework, shopping, looking after their families) were excessively affected, 22 % stated that their working lives were excessively affected and 29 % asserted that their sex lives were excessively affected, while another 34 % reported increased levels of concern and anxiety. Abdollahzadeh et al. [7] stated that 67.8 % of breast cancer patients had unmet supportive care needs. Avci and Kumcagız [8] found that relationships between women and their husbands worsened following breast cancer surgery.

Information Needs of Breast Cancer Patients

After breast cancer surgery, a part of the follow-up treatment is administered in an outpatient setting, and patients are obliged to manage the disease and the effects of treatment at home [9]. When they encounter problems that they cannot solve by themselves in this situation, they must visit a hospital and are sometimes re-hospitalized [10]. Informing patients should include appraising them of the definition of breast cancer, the surgical and medical treatment options, the effects of the disease, and many such subjects as well as provision of the information that they need. Information is crucial to empowering patients, and helping them make decisions about their own care, in addition to managing their health conditions. It has been stated that cancer patients wish to be informed as a method of coping and to help them regain control of their lives [9]. Previous studies have shown that education increases self-care behavior and decreases the anxiety of people with breast cancer [11]. Education also has a positive effect on the emotions and attitudes of people affected by the disease [12], helps them prepare for the future, increases their ability to cope with treatment and its side effects [13], improves their quality of life, and decreases symptoms [14]. In addition, informed patients are also empowered with regard to obtaining the care they want [13]. So et al. [15] found that 55 % of patients wanted to be informed in order to be knowledgeable regarding what they could do to get better, 24 % in order to help themselves, and 21.6 % in order to enable them to manage the disease and its side effects at home. In contrast, the unmet need for information causes anxiety and increases the chance of depression by prohibiting the patient from participating in his or her own care [6]. Nevertheless, patients are generally not well informed, and there are also differences between healthcare personnel and patients in terms of the perception of information needs [14]. Beaver et al. [16] found that breast care nurses were the most important source of information for people with breast cancer. Understanding the information needs of these individuals may enable nurses to help them better cope with treatment, and the side effects of this treatment, thus reducing their anxiety and distress [13, 16]. The objective of the breast care nurse is to provide care, information, and support to women and their families from the moment the patient receives their diagnosis [17]. The treatment and care approaches for breast cancer change rapidly along with the various medical, technological, socio-economic, and cultural factors that affect the information needs of patients. To properly support the patients' continuation of life after breast cancer surgery, their information needs should be constantly evaluated, and the information they need should be provided. Surgical nurses should take more care to ensure that patients who have undergone breast cancer surgery are properly informed during their discharge process.

This study aimed to evaluate the information needs of breast cancer patients who have undergone surgery, and the level to which their needs have been met, in the west of Turkey.

Methods

Ethical Considerations

Ethical approval was provided by the Ethics Committee of the Trakya University Medical Faculty (no. TÜTF-GOKAEK 2013/6—decision number 05/15), and permission to conduct the study was obtained from the director of nursing services and the clinical director. All of the patients received oral information about the study, informed consent was verbally obtained, and participation was voluntary.

Setting and Sampling

This descriptive study was performed between March 2013 and March 2014 in the general surgery clinic of a 1100-bed university hospital in a major city in the west of Turkey. This hospital also has the only oncology clinic in the region, accepting patients from two other major neighboring cities. Women who had undergone breast cancer surgery, did not have cognitive or affective problems, and had volunteered to participate were enrolled in the study. The sampling calculation was carried out using the number of breast cancer patients ($n = 56$) who had received surgical intervention in 2012 at the same hospital in which the study was conducted. The intention had been to have a study sample of 34 patients at a 90 % confidence interval and a 95 % confidence level. However, since participation was voluntary, the final sample number was 55.

Data Collection

A personal information form and the Patient Information Needs Scale (PINS) were used as data-gathering tools. The researcher visited patients that had undergone breast cancer surgery and whose discharge decision had been made in their rooms on the day of discharge. Information was provided with regard to the purpose and method of the study, and oral permission was obtained from the women who agreed to participate. The patients were asked to answer the questions on the data-gathering form, and the answers were recorded.

Personal Information Form

This form was developed by the researcher in order to determine the personal characteristics of the patients. It asked for their age, educational status, marital status, economic status, and form of surgical intervention received.

Patient Information Needs Scale

The PINS was developed by Bubela et al. [18], who also carried out the validity and reliability procedures. Catal and Dicle [19] investigated the Turkish validity and reliability of the scale. The PINS consists of 50 items and seven subscales (medication, life activities, community and monitoring, feelings related to the condition, treatment and complications, quality of life, and skin care).

Patient Information Needs Scale and Subscales

Scale and subscales	Number of items	Items no.	Lowest and highest value to be taken
Medication	8	3, 8, 16, 18, 37, 39, 44, 45	8–40
Life activities	9	2, 5, 14, 17, 27, 28, 29, 30, 48	9–45
Community and monitoring	6	6, 9, 22, 31, 36, 41	6–30
Emotions related to the situation	5	7, 24, 32, 35, 42	5–25
Treatment and complications	9	1, 4, 10, 19, 20, 23, 26, 38, 47	9–45
Quality of life	8	11, 13, 15, 21, 34, 40, 46, 50	8–40
Skin care	5	12, 25, 33, 43, 49	5–25
Total	50		50–250

The scale items were Likert-type and were interpreted as 1 = not important, 2 = somewhat important, 3 = moderately important, 4 = very important, and 5 = extremely important. The evaluation of the scale was carried out through every subscale, as well as the total scale, and the scores obtained from the scale varied from 50 to 250. The scale and subscale scores were divided by the number of questions in the total scale and in every subscale. They were then assigned a score of between 1 and 5, with regard to the level of importance, as follows: 1 = not important, 2 = somewhat important, 3 = moderately important, 4 = very important, and 5 = extremely important. The information need importance level of a patient who took 250 points from the scale is thus interpreted as 250/50 items = 5 (extremely important). Cronbach's alpha for the total scale was 0.95.

The scale items could be modified in terms of the predetermined information needs, whether the information needs were met, and whether prioritized information was provided prior to discharge. Patients could choose the most convenient Likert-type option: 1 = not met at all, 2 = somewhat met, 3 = moderately met, 4 = mostly met, and 5 = completely met. This modified form of the PINS is referred to as the Needs Met Score. After the revision of the scale, the Cronbach's alpha coefficient for the total scale was 0.95 [18, 19].

Data Analysis

The results are reported as mean ± standard deviation or number (percentage). The significance level of patient information needs and meeting of needs of scores of PINS were compared using the Wilcoxon signed-rank test. Subscale scores of PINS at each significance level of patient information needs and meeting of needs were compared using the Freidman test, after which multiple comparisons of subscales were compared using the Wilcoxon signed-rank test with Bonferroni correction. A value of $p < 0.05$ was accepted as the limit for statistical significance. Statistical Package for the Social Sciences, version 20.0, software (IBM, SPSS Inc., Chicago. IL; USA) was used for statistical analysis.

Results

The mean age of the patients was 53.10 +/− 12.28. A total of 58.2 % had received elementary education, 83.6 % were married, 72.7 % had a medium level of income, and 60 % had undergone simple mastectomy surgery (Table 1).

The mean patients' information needs significance score was near "very important" (3.9 +/− 0.6), and the mean meeting of needs significance score was "somewhat met" (2.4 +/− 0.9). When the information needs of the patients and the level to which those needs were fulfilled were compared, the level of fulfillment was statistically significantly lower ($p < 0.001$) (Table 2).

In the comparisons carried out in the subscales groups (medication, life activities, community and monitoring, emotions related to the situation, treatment and complications, quality of life, and skin care), it was determined that information need was between "moderately important" and "very important," and that the level of meeting of needs was between "not met at all" and "somewhat met" ($p < 0.001$) (Table 2).

Among the patient information needs subscale groups, the medication-related information needs significance score (4.2 +/− 0.4/"very important") and the meeting of needs significance score (2.6 +/− 1.1/"somewhat met") were higher than those relating to the remaining subscale groups ($p < 0.001$) (Table 2). Cronbach's alpha of the total scale was 0.98.

Table 1 Personal characteristics ($n = 55$)

Age	($X \pm$ SD) 53.10 ± 12.28	Number	Percentage (%)
Education	Elementary education	32	58.2
	Secondary education	17	30.9
	Undergraduate	6	10.9
Marital status	Married	46	83.6
	Single	9	16.4
Economic situation	Low	14	25.5
	Medium	40	72.7
	High	1	1.8
Surgical intervention	Simple mastectomy	33	60.0
	Modified radical Mastectomy	14	25.5
	Radical mastectomy	8	14.5

Discussion

The results showed that the information needs of breast cancer patients were near to "very important," while the level of meeting their information needs was "somewhat met." This finding is supported by the results of previous studies. For example, Yi et al. [20] determined that the information needs of Korean women with breast cancer were high, Lei et al. [13] found the same with patients undergoing chemotherapy, and Abdollahzadeh et al. [7] determined that patients perceived their information needs to be high (71 %). The results demonstrated that patients who underwent breast cancer surgery needed information to an important degree, and that these needs were not met.

Medication, life activities, community and monitoring, emotions related to the situation, treatment and complications, quality of life, and skin care formed the subscales of the scale. Under these subscales, patients stated that their information needs were between "somewhat important" and "very important," and the level of having their needs met was between "not at all met" and "somewhat met." Lei et al. [13] stated that patients need information and want to obtain as much information as possible with regard to their treatment and physical care, while Wong et al. [21] asserted that patients need information about their home care resources. Tariman et al. [22] and Schmid-Büchi et al. [23] found that patients needed to be informed about supportive care daily life activities, distortion of body image, anxiety and depression, and social support and personal relationships, and that they wanted to receive as much information as possible. The results showed that the information needs of patients that undergo breast cancer surgery are high and extensive. The present study determined that the information needs of patients who undergo breast cancer surgery were inadequately met. Yi et al. [20] found that Korean women suffered from a lack of information about breast cancer, while Cheng et al. [24] asserted that the most commonly unmet information need was that regarding the management of the disease and its side effects. Cechini [6] found that two-thirds of patients studied wanted more information about their disease and its treatment. The results of the present study show that the patients required a great deal of information about the same subjects, but that the level of meeting this need was low. It was determined that the medication subscale was associated with higher levels of need for information and that the need for medication-related information was "somewhat met." It is important for people with cancer to acquire information on medications, since most of them know that medication is often used to treat the disease. Halkett et al. [25] found that the information needs of patients were high during the planning and beginning of treatment. Batte and Odoi-Adome [26] revealed that 41 % of patients were not satisfied with the information they received about their treatment, and 80 % of patients believed that they had

Table 2 Scores of significance level of patient information needs and meeting of needs

	Scores of significance level of patient information needs	Scores of significance level of patient meeting of needs	p^a
Total scale score	3.9 ± 0.6	2.4 ± 0.9	<0.001
Medication	4.2 ± 0.4	2.6 ± 1.1	<0.001
Life activities	3.9 ± 0.6	2.4 ± 1.0	<0.001
Community and monitoring	3.6 ± 0.8	2.2 ± 1.0	<0.001
Emotions related to the situation	3.3 ± 1.1	1.9 ± 1.1	<0.001
Treatment and complications	4.0 ± 0.6	2.5 ± 0.9	<0.001
Quality of life	4.0 ± 0.7	2.4 ± 1.0	<0.001
Skin care	3.9 ± 0.6	2.3 ± 0.9	<0.001
p^b	$p < 0.001$	$p < 0.001$	

[a] Wilcoxon signed-ranks test

[b] Freidman test

not been given the chance to participate in choosing their treatment. Li et al. [27] found that the choice of treatment is one of three important subjects (likelihood of cure, spread of the disease, and treatment options) about which patients need information. Patients who undergo breast cancer surgery want to be further informed with regard to medication.

All of these studies, including the present study, show that information needs, and particularly information needs regarding medication options, are important for individuals who undergo breast cancer surgery.

Limitations

This study was performed in a university hospital with females who underwent three different surgical interventions for breast cancer. Thus, the study may not reflect the information need and fulfillment levels of males with breast cancer who have undergone surgical intervention, or of individuals who have had types of breast cancer surgery other than those that were included in this study.

Conclusions

The results showed that the information needs—primarily regarding medication options—of women who have undergone breast cancer surgery were significant, but the level at which their needs were met was low. We suggest that people who undergo breast cancer surgery should first be given information, including that relating to medication, and that the study should be repeated in a manner that encompasses male patients in the sample group and covers all types of surgical interventions used for breast cancer. The manner in which the information needs of patients who undergo breast cancer surgery will be met, and what can be done to make patients more knowledgeable on the subject, should be the topic of further research.

Acknowledgments The author is grateful to all the participants. I would like to extend special thanks to Professor Dr. Necdet Sut who helped with the statistical analysis.

Compliance with Ethical Standards

Conflict of Interest The author declares that she have no conflict of interest.

References

1. Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D (2011) Global cancer statistics. CA Cancer J Clin 61:69–90
2. World Health Organization (2013) Breast cancer: prevention and control [Internet]. [cited 2015 May 26] Available from: http://www.who.int/cancer/detection/breastcancer/en/index1.html
3. Public Health Institution of Turkey, Republic of Turkey Ministry of Health (2014) Turkey Cancer Statistics [Internet]. [cited 2015 May 26] Available from: http://kanser.gov.tr/Dosya/ca_istatistik/2009kanseraporu.pdf
4. Tastan S, Hatipoglu S, Iyigun E, Kilic S (2012) Implementation of a clinical pathway in breast cancer patients undergoing breast surgery. Eur J Oncol Nurs 16(4):368–374
5. Acil H, Cavdar I (2014) Comparison of quality of life of Turkish breast cancer patients receiving breast conserving surgery or modified radical mastectomy. Asian Pac J Cancer Prev 15(13):5377–5381
6. Cechini I (2013) Women with metastatic breast cancer: life, needs, illness [Internet]. [cited 2015 May 26] Available from: http://www.europadonna.org/wp-content/uploads/Metastatic-breast-cancer-life-needs-illness.pdf
7. Abdollahzadeh F, Moradi N, Pakpour V, Rahmani A, Zamanzadeh V, Mohammadpoorasl A et al (2014) Un-met supportive care needs of Iranian breast cancer patients. Asian Pac J Cancer Prev 15(9): 3933–3938
8. Avci IA, Kumcagız H (2011) Marital adjustment and loneliness status of women with mastectomy and husbands reactions. Asian Pac J Cancer Prev 12(2):453–459
9. Williams SA, Schreier AM (2005) The role of education in managing fatigue, anxiety, and sleep disorders in women undergoing chemotherapy for breast cancer. Appl Nurs Res 18(3):138–147
10. Karamanoglu AY, Ozer FG (2008) Home care for mastectomy patients. J Breast Health 4(1):3–8
11. Harless WG, Zier MA, Harless MG, Duncan RC, Braun MA, Willey S et al (2009) Evaluation of a virtual dialogue method for breast cancer patient education. Patient Educ Couns 76(2):189–195
12. Sainio C, Eriksson E (2003) Keeping cancer patients informed: a challenge for nursing. Eur J Oncol Nurs 7(1):39–49
13. Lei CP, Har YC, Abdullah KL (2011) Informational needs of breast cancer patients on chemotherapy: differences between patients' and nurses' perceptions. Asian Pac J Cancer Prev 12(3):797–802
14. Sharif F, Abshorshori N, Tahmasebi S, Hazrati M, Zare N, Masoumi S (2010) The effect of peer-led education on the life quality of mastectomy patients referred to breast cancer-clinics in Shiraz, Iran 2009. Health Qual Life Outcomes 8:74
15. So WK, Chow KM, Chan HY, Choi KC, Wan RW, Mak SS et al (2014) Quality of life and most prevalent unmet needs of Chinese breast cancer survivors at one year after cancer treatment. Eur J Oncol Nurs 18(3):323–328
16. Beaver K, Twomey M, Witham G, Foy S, Luker KA (2006) Meeting the information needs of women with breast cancer: piloting a nurse-led intervention. Eur J Oncol Nurs 10(5):378–390
17. Karayurt O, Andıc S (2011) Breast care nursing. J Breast Health 7(4):196–202
18. Bubela N, Galloway S, McCay E, McKibbon A, Nagle L, Pringle D et al (1990) The Patient Learning Needs Scale: reliability and validity. J Adv Nurs 15(10):1181–1187
19. Catal E, Dicle A (2008) A validity and reliability study of the Patient Learning Needs Scale in Turkey. Dokuz Eylul Univ Sch Nurs Electron J 1(1):19–32
20. Yi M, Cho J, Noh DY, Song MR, Lee JL, Juon HS et al (2007) Informational needs of Korean women with breast cancer: cross-cultural adaptation of the Toronto informational needs questionnaire of breast cancer. Asian Nurs Res 1(3):176–186
21. Wong RK, Franssen E, Szumacher E, Connolly R, Evans M, Page B et al (2002) What do patients living with advanced cancer and their carers want to know? – A needs assessment. Support Care Cancer 10(5):408–415
22. Tariman JD, Doorenbos A, Schepp KG, Singhal S, Berry DL (2014) Information needs priorities in patients diagnosed with cancer: a systematic review. J Adv Pract Oncol 5(2):115–122

23. Schmid-Büchi S, Halfens RJ, Müller M, Dassen T, van den Borne B (2013) Factors associated with supportive care needs of patients under treatment for breast cancer. Eur J Oncol Nurs 17(1):22–29
24. Cheng KK, Darshini DR, Wong WH, Koh C (2014) Perceived symptoms and the supportive care needs of breast cancer survivors six months to five years post-treatment period. Eur J Oncol Nurs 18(1):3–9
25. Halkett GK, Kristjanson LJ, Lobb E, Little J, Shaw T, Taylor M et al (2012) Information needs and preferences of women as they proceed through radiotherapy for breast cancer. Patient Educ Couns 86(3):396–404
26. Batte A, Odoi-Adome R (2006) Patient involvement in treatment decision making among women with breast cancer: creating person-centred and equitable health service systems [Internet]. [cited 2015 May 26] Available from: http://www.equinetafrica.org/bibl/docs/CBP11EHSbatte.pdf
27. Li PW, So WK, Fong DY, Lui LY, Lo JC, Lau SF (2011) The information needs of breast cancer patients in Hong Kong and their levels of satisfaction with the provision of information. Cancer Nurs 34(1):49–57