



# INFORMATION AND SUPPORT NEEDS OF FIRST-DEGREE FEMALE RELATIVES OF BREAST CANCER PATIENTS

## BİRİNCİ DERECE YAKINLARINDA MEME KANSERİ OLAN KADINLARIN BİLGİ VE DESTEK GEREKSİNİMLERİ

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### Abstract

**Introduction:** The aim of this study was to assess information and support needs (ISNs) of first-degree relatives (FDRs) of women with breast cancer.

**Materials and Methods:** This descriptive and cross-sectional study was conducted in a university hospital's general surgery ward between January and June 2017. The population of the sample consisted of FDRs of women diagnosed with breast cancer and admitted to the hospital ward. The sample consisted of 110 female relatives of the patients, who met the inclusion criteria and agreed to participate in the study. The data was collected with face-to-face interviews using a Personal Information Form and the Information and Support Needs Questionnaire (ISNQ). The results were analyzed using descriptive statistics.

**Results:** The mean scores of importance of information needs ( $3.68 \pm 0.36$ ) was higher than the mean scores of importance of support needs ( $3.24 \pm 0.58$ ). In addition, the mean scores of meeting the information needs ( $2.28 \pm 0.35$ ) was higher than the mean scores of meeting the support needs ( $1.93 \pm 0.34$ ).

**Conclusion:** The findings of the study suggest that the information needs were regarded as more important than the support needs, and the information needs were met more often than the support needs.

Nurses should record the family histories of FDRs of breast cancer patients, assess these histories in light of the danger for breast cancer and meet the information needs of the relatives.

**Keywords:** Breast cancer, high-risk women, first-degree relatives, information and support needs, nursing.

## Öz

Giriş: Bu çalışma, birinci derece yakınlarında meme kanseri olan kadınların bilgi ve destek gereksinimlerini (ISNs) belirlemek amacıyla yapılmıştır.

Gereç ve Yöntem: Araştırma, bir üniversite hastanesinin Genel Cerrahi Servislerinde Ocak-Haziran 2017 tarihleri arasında tanımlayıcı ve kesitsel olarak yürütülmüştür. Araştırmanın evrenini bu tarihler arasında servise yatan meme kanserli kadın hastaların birinci derece kadın yakınları (FDRs), örneklemini ise araştırma kriterlerine uyan ve araştırmaya katılmaya gönüllü olan toplam 110 hasta yakını kadın oluşturmuştur. Veriler “Kişisel Bilgi Formu” ve “Bilgi ve Destek Gereksinimleri Ölçeği” kullanılarak yüz yüze görüşme tekniği ile toplanmıştır. Verilerin analizinde tanımlayıcı istatistikler (sayı, yüzde, ortalama ve standart sapma) kullanılmıştır.

Bulgular: Araştırmada kadınların bilgi gereksinimlerinin önemi puan ortalamalarının (3,68±0,36) destek gereksinimlerinin önemi puan ortalamalarına göre (3,24±0,58) daha yüksek olduğu bulunmuştur. Aynı zamanda, kadınların bilgi gereksinimlerinin karşılanma düzeyi puan ortalamalarının da (2,28±0,35) destek gereksinimlerinin karşılanma düzeyi puan ortalamalarından (1,93±0,34) daha yüksek olduğu tespit edilmiştir.

Sonuç: Sonuç olarak, kadınların bilgi gereksinimlerinin, destek gereksinimlerinden daha çok önem taşıdığı ve bilgi gereksinimlerinin karşılanma düzeylerinin, destek gereksinimlerinin karşılanma düzeylerinden daha yüksek olduğu saptanmıştır.

Anahtar Kelimeler: Meme kanseri, yüksek riskli kadınlar, birinci derece yakınlar, bilgi ve destek gereksinimleri, hemşirelik.

## Introduction

Breast cancer is the most common cancer in women, and is a serious source of concern<sup>1-2</sup>. It affects annually more than 1.5 million people worldwide, and also ranks first among the deaths caused by cancer in women<sup>3</sup>.

As with other types of cancer; genetic, hormonal, and environmental factors all together cause to the formation of breast cancer<sup>4</sup>. A genetic factor is the most important non-changeable factor in the formation of breast cancer<sup>5-6</sup>. 15% of female patients with breast cancer have a family history<sup>7</sup>. It appears that having a family history increases the risk of having breast cancer 1,8 times if a FDR has the disease, and 2,9 times if two people in the family have the disease<sup>8-9</sup>. FRDs may not always be able to cope with the increased risk, face difficulties, and manage the process<sup>10-11</sup>. Therefore, active screening programs for early diagnosis of women at high risk plays an important role in reducing breast cancer mortality rates<sup>12-13</sup>. To diagnose cancer in the early phase, each community should determine own specific

breast cancer risks, determine the risk groups, and execute the screening programs regularly. Assessing and meeting the ISNs of high-risk women and monitoring these groups has been an important step recently in preventing breast cancer<sup>14-15</sup>.

Information, counselling, and emotional support needs of female FDRs of women with breast cancer are increasing, and these women are more vulnerable to stress caused by perception of high cancer risk<sup>16</sup>. Studies also indicate that it is important to meet this information and support to facilitate coping with stress factors related to breast cancer<sup>17-19</sup>.

Nurses, as a part of the healthcare personnel who spend the most time with the relatives of the patients, such as during the early diagnosis stage and the treatment, should not forget they have the responsibility of giving evidence-based education related to the risk factors and the breast health to the women<sup>18,20</sup>. Cognizant of the support needs of the relatives of the patients it is important that nurses also keep informing them and reflect these needs into the care process. This research was conducted to determine the ISNs of FDRs of women with breast cancer and to have a contribution to the existing literature.

## Materials and Methods

- *The Population and the Sample of the Study*

The population of the research consisted of FDRs of women who were diagnosed by breast cancer and were admitted to the general surgery ward during January and June 2017. The sample of the study consisted of 110 female relatives of the patients who met the inclusion criteria and gave consent to contribute to this research.

The inclusion criteria for the study were:

1. Agreeing to participate in the study,
2. Being at least 18 years old,
3. Being able to communicate,
4. One or more relatives having breast cancer,
5. Not having breast cancer herself.

- *Data Collection*

The data was composed using face-to-face meetings after giving the participants information about the study and gaining informed consent. The data was gathered using a Personal Information Form developed by the researchers in line with the literature, and the ISNQ and lasted for approximately 30 minutes. A pilot study was conducted with 10 women, and the data obtained from these interviews were not included in the study.

- *Personal Information Form*

The personal information form included 11 questions such as age, educational position, marital position, occupational position, economic level, and questions related to breast cancer awareness, such as the number of relatives with breast cancer and the relationship, breast self-examination practice frequency, previous support

received regarding breast cancer risks, and the person giving the support.

- *Information and Support Needs Questionnaire (ISNQ)*

The ISNQ was developed by Chalmers et al. (2001) to assess the ISNs of FDRs of women with breast cancer. The questionnaire is a Likert type scale and consists of two scales: "Importance of Needs" and "Meeting Needs"<sup>21,22</sup>.

*1. Importance of Needs Scale:* This scale consists of 29 items. First 18 items of the scale assess information needs, and the remaining 11 items assess the support needs<sup>21-22</sup>. Each item of the scale scores between 1 and 4 (response options 1 to 4 range from "not important" to "very important").

*2. Meeting Needs Scale:* The same items as in the Importance of Needs Scale are used in this scale, however, this scale assesses the level of the needs met. Each item is scored between 1 and 4 (response options 1 to 4 range from "not met at all" to "fully met")<sup>21</sup>. The Cronbach Alpha of Importance of Needs scale modified to Turkish by Zorukos and Karayurt (2008) was 0.81, and 0.83 for Meeting Needs Scale<sup>18</sup>. The Cronbach alpha of Importance of Needs Scale was 0.88 in our study, and 0.86 for Meeting Needs Scale.

- *Ethical Approval*

Permission was obtained via e-mail from Zorukos Tokkaya, who conducted the reliability and validity tests for Turkish. An approval from the Cukurova University's Non-Invasive Clinic Research Ethics Committee (Decision no:14 Date: 04.11.2016) was also obtained to conduct this study, and necessary institutional permissions were obtained from the hospital management where the data was

gathered. In addition, verbal consents were obtained from the participants who agreed to take part in the study, upon informing them regarding the study.

- *Analysis of the Data*

The data were analyzed by means of Statistical Package for the Social Sciences (SPSS) 20.0 program. The results were analyzed using descriptive statistics (frequency, percentage, mean, and standard deviation).

## Results

The mean age of the women contributing in the research was  $41.31 \pm 14.54$ , 30,9 % of the participants were between the age of 31 and 45, 34.5% were primary school graduates, 60.9% were married, and 80% lived in nuclear families. 76.3% of the women were unemployed, and 64.5% of the women reported their incomes being equal to their expenditure. 82.7% of the women had one relative with breast cancer, and 45.5% reported their mother having breast cancer. Findings regarding breast self-examination practices revealed that 44.5%

of the women did not perform breast self-examination. 69.1% of the women reported they had not received any support previously related to the risk of breast cancer. The participants stated having received support previously from doctors (19.1%) and nurses (4.6%). The scale contains 29 items in overall. The primary 18 objects are related to the information needs, and the remaining 11 objects represent the support needs. The mean scores of the importance of the information needs of the participants were higher ( $3.68 \pm 0.36$ ) than the mean scores of the importance of support needs ( $3.24 \pm 0.58$ ). The mean scores for meeting the information needs ( $2.28 \pm 0.35$ ) was higher than the mean scores of meeting the support needs ( $1.93 \pm 0.34$ ) (Table 1).

Three items had the same mean scores as the most important information needs. These items were “Information on how to talk with my relative about her experience with breast cancer”, “Information about ways I can help to decrease my relative's suffering from breast cancer”, and “Information about how to support my relative during her experience with breast cancer”.

**Table 1.** Item Mean Scores of Importance of ISNs and Meeting Needs Scales of the Women

	Importance of Needs		Meeting Needs	
	Information Needs	Support Needs	Information Needs	Support Needs
Item number	18	11	18	11
Levels of Importance of Information and Support Needs	$3.68 \pm 0.36$	$3.24 \pm 0.58$	$2.28 \pm 0.35$	$1.93 \pm 0.34$

**Table 2.** Information (1-18) and Support (19-29) Needs Questionnaire's Ranked Item Mean Scores (n = 110)

Item No	Needs	Importance	Needs Met
1*	Information on how to talk with my relative about	3.87 ± 0.43	1.81 ± 0.63
12*	Information about ways I can help to decrease my	3.87 ± 0.39	1.47 ± 0.66
13*	Information about how to support my relative	3.87 ± 0.41	1.50 ± 0.60
4*	Information about the emotional reactions of	3.86 ± 0.46	2.42 ± 0.60
5*	Information about the emotional reactions and	3.85 ± 0.54	2.59 ± 0.51
10*	Information about how to talk with my children	3.80 ± 0.59	1.64 ± 0.67
6*	Information about how to talk with my family (spouse/partner,children	3.78 ± 0.58	2.05 ± 0.71
9*	Information about my daughter's risk for breast	3.75 ± 0.72	2.07 ± 0.59
2*	Information about what causes breast cancer.	3.73 ± 0.62	2.45 ± 0.66
21**	Regular examinations of my breasts by a knowledgeable health	3.67 ± 0.65	2.52 ± 1.09
15*	Information and demonstration of breast self	3.65 ± 0.77	3.27 ± 0.90
7*	Information about my own personal risk for breast	3.63 ± 0.86	2.19 ± 0.57
23**	Support to help me deal with my worries about my	3.63 ± 0.70	2.45 ± 0.92
14*	Information about possible risk factors for breast cancer (e.g. high fat diet, hormone replacement therapy, etc.).	3.62 ± 0.70	2.75 ± 0.55
3*	Information about the treatments for breast cancer	3.61 ± 0.68	2.53 ± 0.57
24**	Have a knowledgeable health professional watch me do breast self-examination and check that I am doing it	3.59 ± 0.84	1.10 ± 0.33
26**	Have a group to attend for support.	3.56 ± 0.82	3.36 ± 0.75
16*	Information about mammography screening (i.e.	3.53 ± 0.81	3.15 ± 0.95
17*	Information about how to change my behaviour to	3.52 ± 0.83	3.12 ± 0.76
11*	Information about changes in my health habits	3.51 ± 0.79	2.83 ± 0.54
8*	Information about how to talk with my family about	3.50 ± 0.90	1.81 ± 0.68
28**	Support to help develop a "plan" if I should get	3.49 ± 0.88	2.39 ± 0.85
18*	Information about genetic counseling for myself and	3.44 ± 0.89	1.53 ± 0.69
27**	Support to help me "come to terms" with my	3.43 ± 0.96	2.37 ± 0.91

22**	Support to help me carry out breast self-examination	3.24 ± 0.93	2.88 ± 0.85
19**	Reminders for mammography appointments (i.e.	2.99 ± 1.03	1.00 ± 0.00
29**	Support to help me decrease my worries about	2.87 ± 1.28	1.15 ± 0.47
20**	Reminders for breast self-examinations (i.e. sent out	2.77 ± 1.06	1.00 ± 0.00
25**	Have someone to talk to about my worries about my	2.45 ± 1.20	1.01 ± 0.10

\*Items of information needs    \*\*Items of support needs

Three most important support needs items were stated respectively as “Regular examinations of my breasts by a knowledgeable health professional” (3.67 ± 0.65), “Support to help me deal with my worries about my relative's illness” (3.63 ± 0.70) and “Have a knowledgeable health professional watch me do breast self-examination and check that I am doing it properly” (3.59 ± 0.84) (Table 2).

The first three items of information need to be stated as being met the most by the women were “Information and demonstration of breast self-examination” (3.27 ± 0.90), “Information about mammography screening” (3.15 ± 0.95), and “Information about how to change my behaviour to promote my health” (3.12 ± 0.76). The first three items of support need stated as being met the most by the women were stated respectively as “Support to help me carry out breast self-examination on a regular basis” (2.88 ± 0.85), and “Regular examinations of my breasts by a knowledgeable health professional (2.52 ± 1.09) (Table 2.).

## Discussion

FDRs knowing what information and support they need will facilitate the approach of healthcare professionals. This study assessed the ISNs, and the needs met, of FDRs of women who had breast cancer. The mean scores of the importance of

information needs (3.68 ± 0.36) were higher than the mean scores of the importance of support needs (3.24 ± 0.58) (Table 1). The results of the study are similar to the literature<sup>6</sup>. In a study by Andiç and Karayurt (2012), the mean scores of the importance of information needs (3.72 ± 0.19) were higher than the mean scores of the importance of support needs (3.24 ± 0.41)<sup>23</sup>. It should be borne in mind that FDRs of women with breast cancer are not only a source of support for their loved ones, but their health can be enhanced by providing early diagnosis.

The items of the importance of information needs stated as the most significant by the women had equal scores (3.87) and were “Information on how to talk with my relative about her experience with breast cancer”, “Information about ways I can help to decrease my relative's suffering from breast cancer”, and “Information about how to support my relative during her experience with breast cancer” (Table 2). The results of the study partially differ from the literature<sup>24-26</sup>. These behavioral differences may originate from ethnic background, and cultural structure of the society may result in not paying attention to their own risks, focusing on the relatives' disease instead. FDRs are interested in the psychological condition of the patient, and try to engage in beneficial communication with the patient. It is possible that the relatives of the patients are concerned about the psychological condition of the patient and try to engage in constructive

communication. In addition, the statements of the participants might indicate that the healthcare personnel do not assess the psychological conditions of the patients adequately during treatment and care.

Three of the most valued importance of support needs items were stated respectively as “Regular examinations of my breasts by a knowledgeable health professional” ( $3.67 \pm 0.65$ ), “Support to help me deal with my worries about my relative's illness” ( $3.63 \pm 0.70$ ) and “Have an expert health professional watch me do breast self-examination and check that I am doing it properly” ( $3.59 \pm 0.84$ ) (Table 2). Three of the most valued importance of support needs items in a study by Tunin et al. (2010) were stated as “Regular examinations of my breasts by an expert health professional”, “Have an expert health professional watch me do breast self-examination and check that I am doing it properly”, and “Have someone to talk to about my worries about my relative with breast cancer”<sup>26</sup>. The support needs of the women taking part in this study are in accordance with the literature<sup>14,27</sup>. This suggests that the participants need professional support and validating from the healthcare personnel. It is possible that the healthcare personnel do not allocate enough time to teach breast self-examination, explain the importance of breast self-examination, and have activities regarding the concerns related to the disease to the women who are at high danger of breast cancer.

The mean scores of meeting information needs were higher ( $2.28 \pm 0.35$ ) than the mean scores of meeting support needs ( $1.93 \pm 0.34$ ) (Table 1). These findings are in accordance with the literature<sup>14,26,28</sup>.

The highest three items reported by the participants regarding meeting information needs were respectively “Information and demonstration of breast self-examination”, ( $3.27 \pm 0.90$ ), “Information about mammography screening ( $3.15 \pm 0.95$ ) and “Information about how to change my behaviour to promote my health” ( $3.12 \pm$

$0.76$ ) (Table 2). The findings regarding meeting information needs reported by the participants are in accordance with the literature<sup>24,26,28</sup>. The results demonstrate that women in the risk group receive sufficient information regarding mammography, and it is important to increase education provided on breast cancer screening<sup>29,30</sup>. Advances in medical science, and specialization of health professionals in their own field may have contributed to the progress in this area. Information needs to be stated as being met the least in the participants were “Information about ways I can help to decrease my relative's suffering from breast cancer” ( $1.47 \pm 0.66$ ), “Information about how to support my relative during her experience with breast cancer” ( $1.50 \pm 0.60$ ), and “Information about genetic counselling for myself and my children” ( $1.53 \pm 0.69$ ). In a study these findings by Tunin et al. (2010), it shows parallelism with the research<sup>26</sup>. These findings suggest that women who are at high risk do not have enough information on how to discuss the experienced sadness and how to support relatives with breast cancer. Not knowing how to discuss the risk of having breast cancer herself or the possibility of their children having it, and having information needs regarding genetic consulting been met very insufficiently might be an indication that the healthcare personnel give mainly information about the illness and the treatment, but do not meet the information needs regarding correct and helpful communication between the patients and their families. In addition, suggest that healthcare personnel do not carry out their role as a genetic consultant to meet the information needs of the patients. Different studies have demonstrated that measuring insufficiency in genetic risk knowledge is highly challenging, there is a lack of adequate counselling, and insufficient information regarding the issue<sup>31-33</sup>.

The first three support needs items reported as being met the highest by the participants were “Reminders for breast self-

examinations” (3.36 ± 0.75), “Support to help me carry out breast self-examination on a regular basis” (2.88 ± 0.85) and “Regular examinations of my breasts by a knowledgeable health professional” (2.52 ± 1.09) (Table 1). Support needs items reported as not being met by the participants were “Reminders for mammography appointments” and “Reminders for breast self-examinations” (Table 1). The support needs of the participants in this study included reminders for mammography and for self-examinations, and although these results differ from the studies made outside of Turkey, they are in accordance with the studies conducted in Turkey<sup>24-26</sup>. The healthcare system in Turkey does not have practices reminding the women their mammography appointments and breast self-examinations, which might be the reason the findings differ in Turkey. Although the findings of the study partly differ from the literature conducted outside of Turkey due to cultural differences, technological advances, and the changes in the health system, the ISNs of women regarding breast cancer are similar in studies conducted in Turkey and in the world.

As a conclusion: the information needs were regarded as more significant than the support needs of the participants, and information needs were met more often than the support needs. As a member of a professional occupation, nurses should record the family histories of FDRs of breast cancer patients, assess these histories in light of the danger for breast cancer and meet the information needs of the relatives. In addition, conducting further studies investigating the ISNs of the FDRs of women with breast cancer is suggested.

## Conflict of Interest

The authors declared they do not have anything else to disclose regarding conflict of interest with respect to this manuscript.

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## Ethical approval

Cukurova University’s Non-Invasive Clinic Research Ethics Committee. (Decision no:14 Date: 04.11.2016)

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