

## RESEARCH ARTICLE

# Determination of Information and Support Needs of First Degree Relatives of Women with Breast Cancer

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### Abstract

**Background:** Breast cancer is the most frequent type of cancer among women in the world and the most common cause of deaths from cancer in females. In Turkey, breast cancer comes first in the list of the most frequent ten cancer types seen in women. As the incidence rate of breast cancer is high, many women having breast cancer in the family experience the breast cancer at secondhand. This study was carried out in an attempt to determine the information and support needs of women whose first-degree relatives have breast cancer and to what extent these needs are met. **Methods:** The research sample consisted of 156 women. Questionnaire Form and Information and Support Needs Questionnaires were used as the data collection tools. **Results:** Information need score averages ( $\bar{x}$ : 3.72±0.19) of women included in the research sampling were found to be higher than their score averages of support needs ( $\bar{x}$ : 3.24±0.41). **Conclusion:** Information needs which were indicated by women as very important were related to treatment, symptoms of breast cancer and breast self examination (BSE), while support needs which were indicated by women as very important were learning how to perform BSE, women's anxiety for themselves and their relatives regarding breast cancer and having their breasts examined by a health professional. It is recommended that nurses and other medical staff should give information to women whose first-degree relatives have breast cancer about the disease, its etiology, scanning, diagnosis, treatment options and protection as well as prevention.

**Keywords:** Women at high risk of breast cancer - information and support needs - nursing intervention

*Asian Pacific J Cancer Prev*, 13 (9), 4491-4499

### Introduction

Breast cancer represents a serious health concern for women. Breast cancer is the most frequent type of cancer among women in the world (28%) and the most common cause of deaths (15%) from cancer (ACS, 2010a). There are about 2.5 million women with a history of breast cancer in the world (ACS, 2010a). Incidence rates are higher in Europe and America but lower in Africa and eastern Mediterranean countries (WHO, 2004). In Turkey, breast cancer comes first among the most frequent ten cancer types seen in women (with a rate of 37.60 per one hundred thousand) (Sağlık Bakanlığı, 2006). Breast cancer incidence rate is more than two times higher in western part of Turkey (50/100.000) when compared to the eastern part of Turkey (20/100.000) due to "Westernizing lifestyle" (Özmen, 2008).

The high incidence of breast cancer in the world increased the awareness for and concerns about the breast cancer risk (Stacey et al., 2002). The concept of risk has psychological and social dimensions as well as its medical and epidemiological dimensions. The disease, treatment and recovery process can be demanding for patients and their families (Schmid-Büchi et al., 2008). Breast cancer changes women's lives (Arman et al., 2008). Women with the breast cancer are influenced intensely by the emotional

problems caused by this disease with their relatives (Gross, 2000; Vogel, 2003). The adolescents whose mothers have breast cancer clearly reported fears, uncertainties, and feelings of isolation in response to their mothers' cancer diagnoses (Kristanjon et al., 2004). It is important to inform the women at high risk of breast cancer and follow up them carefully for prevention and early detection of breast cancer (Karayurt, 2008).

Breast cancer incidence and death rates generally increase with age (Gross, 2000; ACS, 2010a). Ninety-nine percent of the breast cancer cases is seen in women and 54 % of these women is at the age of 40 and over (ACS, 2010b; Smeltzer and Bare, 2010). The possibility of the breast cancer to be seen in men is 1%. Risk factors of the breast cancer which can not be changed are gender, age, genetic risk factors (Breast Cancer 1 (BRCA-1) and Breast Cancer 2 (BRCA-2) gene mutations), family history, the history of breast cancer, race, density of the breast tissue, benign breast conditions, early menarch, late menopause, previous radiation exposure to the chest and exposure to diethylstilbrestol medicine. As for the risk factors that can be changed, they are lack of child or the age of the first pregnancy to be over 30, postmenopausal hormone treatment, combined use of estrogen and progesteron, breast feeding, alcohol consumption, postmenopausal obesity and inadequacy of physical activity (ACS,

2010b).

Family history is extremely important among the risk factors. It is estimated that hereditary breast cancer accounts for approximately 5-10% of all breast cancer cases (Shienfield and Albert, 2003). Women which carry a high genetic risk of breast cancer struggle for life with the knowledge (Baumann, 2006). Patients have different reasons for seeking cancer genetic advice but they predominantly want to receive specific information to reduce their anxiety about their own and children's risks, and to gain access to surveillance and genetic testing (Iredale et al., 2003). Speice et al. explored that people should be encouraged to talk with several people prior to genetic testing because of the range and variety of experiences encountered (Speice et al., 2002).

Risk estimation based on the family history varies depending on the age of the family member at the time of diagnosis, the age of the woman, the number of the affected relatives and it is estimated that the women with first degree relatives with breast cancer carry the breast cancer risk two times much more than the general woman population (Gross, 2000; McPherson et al., 2000; Vogel, 2000; Hulka and Moorman, 2001). However, it was determined in the study conducted by Haan et al. that the age of the mother or grandmother did not play an important role in the breast cancer risk of her daughter or granddaughter (Haan et al., 2010).

Women were selected to the High-Risk Breast Assessment Clinic if they met any one of the absolute criteria:(a) family history of breast or ovarian cancer in two or more first - or second- degree relatives, (b) breast cancer occurring in one first or second-degree relative when bilateral or premenopausal was at onset, (c) atypical hyperplasia, (d) lobular carcinoma in situ, or (e) a positive genetic screen (Stacey et al., 2002). It was expressed that women at high risk with family history of breast cancer experienced fear, anxiety, anger, uncertainty, hopelessness (Chalmers and Thomson, 1996: 2003; Gross, 2000; Kristjanson et al., 2004; Cohen, 2006). It was also emphasized that women reflected the anxiety or fear that they felt due to breast cancer to their husbands and children and thus, the breast cancer should be evaluated as the disease of the family (Karayurt, 2008). Women with primary relatives with breast cancer may experience difficulty attending to their own preventive self-care needs when they are concerned about the health of their relative with breast cancer (Chalmers and Thomson, 1996). It was reported that risk perceptions of women having breast cancer in the family history caused anxiety. A high level of cancer anxiety and oversensitiveness frequently result in performing the breast self examination (BSE) or avoid BSE (Chalmers and Thomson, 1996). On the other hand, it was found that there was no difference between the women with a family history of breast cancer and the women without a family history of breast cancer in terms of adaptation to the early detection practices (Chalmers et al., 2003). It was found in the study conducted by Cohen (n:489) that a majority of women did not take the clinical breast examination and mammography (Cohen, 2006). Norman and Brain reported that women having breast cancer in the family history in England (n:567) performed

BSE irregularly. Women showed such an attitude due to the fact that they did not find themselves competent on this matter, they did not know the benefits of BSE very well and they had emotional barriers and breast cancer anxieties (Norman and Brain, 2005). It was found in the study conducted by Sinicrope et al. in America that daughters of women with breast cancer wanted to receive information as regards to performing the BSE, clinical breast examination, taking mammography, risk of having breast cancer and the healthy life style (Sinicrope et al., 2009). Another study explored that women at high risk of breast cancer (n:97) wanted to learn the breast cancer screening, breast cancer risk, life style changes for lower risk, hormone replacement treatments and protection with medicine (Stacey et al., 2002). Iredale et al. reported that women at high risk of breast/ovary cancer in England needed general information about new developments in genetics, new developments in the screening and treatment of breast and ovary cancer, hormone replacement treatment (HRT) and its side effects. Chalmers et al. conducted a descriptive study (n:261) in Canada by using the information and support needs questionnaire (ISNQ) in order to determine the information and support needs of women with breast cancer in the first degree relatives and to what extent and by whom these needs are met. It was determined in this study that women placed importance on information about the BSE, clinical breast examination and mammography screening. Support topics that women participating in the study attached importance to included being examined by the health professional, being controlled while performing the BSE and receiving support in order to perform BSE regularly (Chalmers et al., 2003). Tunin et al. conducted a descriptive study (n:128) in Israel by using the same scale so as to determine the information and support needs of women with breast cancer in the first degree relatives and to what extent and by whom these needs are met. At the end of the study, it was found that women attributed importance to mammography screening, risk of having breast cancer and reasons of breast cancer. Besides, the support topics that women found important were clinical breast examination, BSE and how to communicate with the relative having breast cancer. It was stated in the study that most of the information and support needs were met at low levels (Tunin et al., 2010).

The obtained data suggest that a psychological intervention may reduce cancer-specific psychological distress experienced by women at high risk of breast cancer (Hurt et al., 2001). Chalmers and Thomson detected that information, support and communication facilitated adaptation to breast cancer risk (Chalmers and Thomson, 1996).

A limited number of studies were found in Turkey about the information and support needs of women with breast cancer in the first degree relatives. In the study conducted by Gençtürk and Akyolcu, it was specified that 62.5 % of the first degree relatives of the women having breast cancer did not know how to protect themselves from breast cancer and 43.7% of them did not perform the protection/early detection method against breast cancer. An increase was assessed in the information scores

**Table 1. Rank Ordering of Importance of Needs by Mean from Very Important (4) to Not Very Important (1) and Needs Met by Mean from Met Fully (4) to Not Met (1) (n: 156)**

Item	Needs	$\bar{x} \pm SD$	$\bar{x} \pm SD^{**}$
3	Information about the treatments for breast cancer (eg, radiation, chemotherapy, side effects, etc)	4.00±0.00	3.31±0.76
2	Information about what causes breast cancer	3.99±0.08	2.66±0.90
14	Information about possible risk factors for breast cancer (eg, high-fat diet, hormone replacement therapy, etc)	3.99±0.08	1.88±0.88
15	Information and demonstration of breast self-examination	3.99±0.08	2.14±1.03
17	Information about how to change my behavior to promote my health	3.97±0.15	2.02±0.92
24	Have a knowledgeable health professional watch me do breast self-examination and check whether I am doing it properly*	3.97±0.19	1.23±0.72
7	Information about my own personal risk for breast cancer	3.96±0.21	3.00±1.00
16	Information about mammography screening (ie, how often I should be screened)	3.95±0.23	3.10±1.03
11	Information about changes in my health habits that might lower my risk for breast cancer	3.94±0.22	2.10±0.83
9	Information about my daughter's risk for breast cancer	3.87±0.47	2.16±0.90
5	Information about the emotional reactions and physical symptoms of women who are undergoing treatment for breast cancer	3.81±0.46	2.69±0.66
18	Information about genetic counselling for myself and my children	3.78±0.49	1.29±0.73
4	Information about the emotional reactions of women who are newly diagnosed with breast cancer	3.76±0.51	1.90±1.88
1	Information on how to talk with my relative about her experience with breast cancer	3.73±0.66	1.35±0.85
28	Support to help develop a "plan" if I should get breast cancer*	3.70±0.45	1.30±0.79
13	Information about how to support my relative during her experience with breast cancer	3.57±0.49	1.37±0.92
22	Support to help me carry out breast self-examination on a regular basis*	3.44±0.82	1.31±0.78
6	Information about how to talk with my family (spouse/partner, children, siblings, etc) about my relative's experience with breast cancer	3.32±0.79	1.33±0.81
29	Support to help me decrease my worries about getting breast cancer*	3.30±0.53	1.41±0.89
21	Regular examinations of my breasts by a knowledgeable health professional (ie, physician, nurse, etc)*	3.27±0.71	1.25±0.74
12	Information about ways I can help to decrease my relative's suffering from breast cancer	3.21±0.53	1.40±0.96
8	Information about how to talk with my family about my risk for breast cancer	3.12±0.63	1.34±0.85
25	Have someone to talk to about my worries about my relative with breast cancer*	3.10±0.60	1.28±0.74
23	Support to help me deal with my worries about my relative's illness*	3.08±0.52	1.30±0.88
10	Information about how to talk with my children about their possible risks for breast cancer	3.07±0.94	1.26±0.74
27	Support to help me "come to terms" with my feelings of risk for breast cancer*	3.02±0.76	1.32±0.88
26	Have a group to attend for support*	2.97±0.66	1.16±0.66
20	Reminders for breast self-examinations (ie, sent out in the mail or by telephone)*	2.89±1.06	1.17±0.63
19	Reminders for mammography appointments (ie, sent out in the mail or by telephone)*	2.87±1.13	1.16±0.66

**Table 2. Sources and Desired Sources of Information and Support for Concerns about Breast Cancer Risk (n: 156)**

Sources	Reporting of information some or a lot n (%)	Reporting of desiring some or a lot of information n (%)
Information: Oncologist	44 (28.2)	78 (50)
Surgeon	23 (14.7)	37 (23.7)
Television	22 (14.1)	-
Family	5 (3.2)	-
Nurses	3 (1.9)	8 (5.1)
Family Doctor	3 (1.9)	31 (19.9)
Books	2 (1.3)	-
Pamphlets	1 (0.6)	2 (1.3)
Newspapers	1 (0.6)	-
Friends	-	-
Magazines	-	-
Support: Family	48 (30.8)	14 (9.0)
Oncologist	13 (8.3)	29 (18.6)
Friends	11 (7.1)	1 (0.6)
Nurse	2 (1.3)	44 (28.2)
Family Doctor	-	30 (19.2)
Support group/volunteers	-	30 (19.2)
Doctor	-	8 (5.1)

averages of women with breast cancer in the first degree relatives after they were trained regarding the protection from breast cancer. However, they could not reflect these information to their behaviors (Gençtürk and Akyolcu, 2005). Aslan and Çeber indicated that information needs of women having breast cancer in the first degree relatives were more important than their support needs (Aslan and Çeber, 2011).

Complex information and skills are needed in order to prevent breast cancer. Nurses have important roles in informing the first degree relatives of women having breast cancer and in helping them cope with their problems. Nurses should meet the information and support needs of women at high risk of breast cancer by using the evidence-based information and practices (Karayurt, 2008).

Objective of this research was to determine information and support needs of women having breast cancer in the first degree relatives and to what extent these needs are met. Determining the information and support needs of women having breast cancer in the first degree relatives and to what extent these needs are met will help planning and applying the appropriate nursing interventions for women at high risk as they have first degree relatives suffering from breast cancer. Besides, it was aimed to

answer the following questions in the study: 1) What are the information sources of women having breast cancer in the first degree relatives as regards to the breast cancer? 2) What are the sources from which women having breast cancer in the first degree relatives want to receive information about the breast cancer? 3) What are the support sources of women having breast cancer in the first degree relatives regarding the breast cancer risk? 4) What are the sources from which women having breast cancer in the first degree relatives want to receive information regarding the breast cancer? 5) What are the status of women having breast cancer in the first degree relatives in applying the breast cancer early detection methods (BSE, clinical examination, mammography)?

## Materials and Methods

A descriptive and cross-sectional design was used in this study. Research was conducted in chemotherapy units, Radiation Oncology and Hematology Oncology policlinics of two university hospitals and a research and training hospital located in İzmir in western part of Turkey between August 2010 and February 2011.

Sample of the research was composed of 156 first degree relatives of women applying to the abovementioned centers with the complaint of breast cancer. All these women met the following sample characteristics.

A convenience sample of women who met the following criteria was included: 1) Providing an informed consent to participate 2) Having one or more first degree relatives with breast cancer 3) Not being diagnosed with breast and gynaecologic cancer 4) Being 18 years old or older 5) Having the abilities to speak, read and write in Turkish and 6) Not having vision or hearing loss that will impair communication.

### Instruments

“Questionnaire Form” including information about the women and “Information and Support Needs Scale” were used in data collection.

### Questionnaire Form

Questionnaire Form is composed of 21 items in order to determine the participants' age, education level, profession, income level, civil status, the number of the first degree relatives with breast cancer, identity of these first degree relatives, how old their relatives were when they were diagnosed with breast cancer, how old the participants were when their relatives were diagnosed with breast cancer, what are the sources of their previous information regarding the breast cancer risk, from whom they received the previous supports concerning the breast cancer risk, from where they want to receive information and support and their practices aimed at breast cancer early detection and awareness.

### The ISNQ (Information and Support Needs Questionnaire)

The ISNQ was developed by Chalmers et al to assess information and support needs of women whose primary relatives had breast cancer (Chalmers et al, 2001). The questionnaire was composed of 2 scales: the Importance

Scale and Needs Met Scale. 1) The Importance Scale was composed of 29 items. 18 items were about information needs and 11 items were about support needs. The instrument helps to prioritize the needs. 2) The Needs Met Scale was composed of 29 items and helps to prioritize the needs met. Both instruments use Likert-like response options; each item had a 4-point scale, with 1 as not important, 2 as important, 3 as quite important, and 4 as very important in the Importance Scale and 1 as not met at all, 2 as met, 3 as quite met, and 4 as met fully in the Needs Met Scale. In addition, there was a choice of not applicable (0=not applicable). Participants in the study were asked to respond to each of the 29 statements using 2 response formats. Initially they were asked to assess how important each need for information or support was at the time of data collection using the response options of very important to not very important (score of 4-1). These items formed the Importance Scale of the ISNQ. Then, they were asked to assess to what degree each need had been met from the range of not met at all to met fully (score of 1-4). These items formed the Needs Met Scale of the ISNQ. After that, they assessed the degree to which each need had been met (response options from 4 to 1 as met fully to not met at all). A total score for each scale was not obtained, but a mean score for each item was determined, and thus, how important the needs were and the degree to which the needs were met were determined (Chalmers et al, 2001).

In the original instrumentation development and testing of the ISNQ which were completed by Chalmers et al, evidence was reported for content validity and it was based on in-depth interviews with women whose primary relatives had breast cancer in qualitative studies. The women were asked openended questions about whether their any other needs were not covered in the questionnaire. However, they did not specify any more needs. Chalmers et al. reported that this finding supported content validity of the questionnaire.

*Reliability coefficients for the original ISNQ:* Cronbach coefficient  $\alpha$  values were 0.92 for the Importance Scale and 0.92 for the Needs Met Scale. Test-retest reliability using Pearson correlation coefficient was 0.79 for the Importance Scale ( $P<0.001$ ) and 0.73 for the Needs Met Scale ( $P<0.001$ ) ( $n=239$ ). The test-retest reliability with Spearman correlation coefficient was 0.80 for the Importance Scale ( $P<0.001$ ) and 0.74 for the Needs Met Scale ( $P<0.001$ ) ( $n=239$ ). Item-to-total correlation coefficient was calculated to determine the content validity of the scale and found to be more than 0.33 for each item (Zorukoş, 2010).

Original ISNQ was adapted to Turkish by Zorukoş and Karayurt (2010). The ISNQ Turkish version's (ISNQ-Tr) linguistic validity, translation, back translation, and content validity were tested with expert opinions.

*Reliability coefficients for the ISNQ-Tr:* Item-to-total correlation scores ranged from 0.22-0.72 for the Importance Scale and from 0.23-0.60 for the Needs Met Scale. Cronbach  $\alpha$  coefficients were 0.81 and 0.83 for the Importance Scale and the Needs Met Scale. Test-retest reliability coefficients were 0.94 for the Importance Scale and 0.96 for the Needs Met Scale. Test-retest reliability

coefficients were statistically significant ( $P < 0.001$ ). There was no significant difference between the mean scores of the Importance Scale and the Needs Met Scale in the first and the second tests ( $P > 0.05$ ) (Zorukoş and Karayurt, 2010).

In this study, internal consistency Cronbach Alpha reliability coefficient was found as 0.84 for the Importance Scale and Cronbach Alpha reliability coefficient was found as 0.97 for the Needs Met Scale.

#### *Data collection*

Data were collected through face-to-face interviews with breast cancer patients' daughters and sisters. Each participant required approximately 25 minutes to complete both instruments.

#### *Statistical Analysis*

We used SPSS 15.0 (Statistical Package for the Social Sciences) to analyze our data. Descriptive statistics, number, percentage, average values and standard deviation were used in the analysis of the data.

## **Results**

#### *Sample Characteristics*

Age average of the women included in the research sample was  $41.02 \pm 12.22$  by varying between 18 and 65. Forty-seven point four percent of the women was high school graduates, 54.5% of them was housewives and 80.1% of them was married. The ratio of women having breast cancer in sister/sisters was 50.6%. Besides, 82.1 % of the participants had income equal to expense.

#### *Women's Assessment of The Most Important Information and Support Needs*

Importance of information and support needs score averages of women included in the research sample were indicated in the Table 1 from the highest to the lowest (4:very important, 1:not important).

There are 29 items in the scale in total and the first 18 of these items are related to information needs while the other 11 items are related to support needs. Overall, information needs ( $\bar{x} : 3.72 \pm 0.19$ ) were rated as more important than support needs ( $\bar{x} : 3.24 \pm 0.41$ ). The following information need items were specified as very important by the women included in the research. The first one was the information about the treatments of breast cancer ( $\bar{x} : 4 \pm 0.00$ ); second three items with the same score were "information regarding the reasons of breast cancer" ( $\bar{x} : 3.99 \pm 0.08$ ), "information regarding the possible risk factors of breast cancer" ( $\bar{x} : 3.99 \pm 0.08$ ), "information and demonstration of breast self-examination" ( $\bar{x} : 3.99 \pm 0.08$ ); and the third one was "information as regards to how to change my behavior in order to promote my health" ( $\bar{x} : 3.97 \pm 0.15$ ) (Table 1).

The first three items stated as very important by the women among the support need items were as follows in order of importance: "having a knowledgeable health professional to watch me performing breast self-examination and to check whether I am doing it properly"

( $\bar{x} : 3.97 \pm 0.19$ ), "having support to help me develop a 'plan' if I have breast cancer" ( $\bar{x} : 3.70 \pm 0.45$ ) and "having support to help me carry out breast self-examination on a regular basis" ( $\bar{x} : 3.44 \pm 0.82$ ) (Table 1).

#### *The Degree to Which Women Considered That Their Needs Had Been Met*

Distributions of degrees to which the information and support needs of women were met were given in the Table 1 from the highest average to the lowest average.

Score averages of women included in the research sample in terms of the levels to which their information needs were met ( $\bar{x} : 2.01 \pm 0.64$ ) were, in general, found higher than the score averages of the levels to which their support needs were met ( $\bar{x} : 1.26 \pm 0.68$ ). The first three information need items specified as met fully by the women participating in the research were "information concerning the treatments of breast cancer (eg., radiation, chemotherapy, side effects, etc.)" ( $\bar{x} : 3.31 \pm 0.76$ ), "information about the mammography screening (i.e. how often should I take the screening)" ( $\bar{x} : 3.10 \pm 1.03$ ), and "information about my own personal risk for breast cancer" ( $\bar{x} : 3.00 \pm 1.00$ ) (Table 1).

Information need items specified by the women included in the research as not met at all were "information as regards to how to talk with children about their possible risks for breast cancer", "information about how to talk with my family about my risk for breast cancer" and "information about genetic counselling for myself and my children".

The first three support need items that women defined as met fully were "having support to help me decrease my worries about having breast cancer" ( $\bar{x} : 1.41 \pm 0.89$ ), "having support to help me "come to terms" with my feelings of risk for breast cancer" ( $\bar{x} : 1.32 \pm 0.88$ ) and having support to help me carry out breast self-examination on a regular basis" ( $\bar{x} : 1.31 \pm 0.78$ ) (Table 1).

However, the support need items specified by the women participating in the research as not met at all were "reminders for mammography appointments (i.e. sending by mail or reminding by telephone)", "having a group to attend for support", "reminders for breast self-examinations (eg. sending by mail or reminding by telephone)", "information concerning the genetic counselling for myself and my children" and "having a knowledgeable health professional to watch me performing the breast self-examination and to check whether I am doing it properly".

#### *Sources and Desired Sources of Information for Concerns of Breast Cancer Risk*

Women included in the research sample listed their sources of information as follows: "oncologist" was at the top with a ratio of 28.2% (n:44), the second one was "surgeon" with a ratio of 14.7% (n:23), the third one was "television" with a ratio of 14.1% (n:22) and the fourth one was "nurse" with a ratio of 1.9% (n:3). As for the sources that women wanted to get information in first place, participants listed them as "oncologist" with a ratio of 50% (n:78), "surgeon" with a ratio of 23.7% (n:37),

“family doctor” with a ratio of 19.9 % (n:31) and finally “nurse” with a ratio of 5.1% (n:8) (Table 2).

#### *Sources and Desired Sources of Support for Concerns of Breast Cancer Risk*

Women participating in the research stated their primary sources of support as “family” with a ratio of 30.8% (n:48), “oncologist” with a ratio of 8.3% (n:13), “friends” with a ratio of 7.1% (n:11) and “nurse” with a ratio of 1.9% (n:3). However, women specified the primary sources that they wanted to get information as “nurse” with a ratio of 28.2 % (n:33), “family doctor” with a ratio of 19.2 % (n:30), “support group/volunteers” with a ratio of 19.2 % (n:30) and the third one “oncologist” with a ratio of 18.6 % (n:29) (Table 2).

#### *Preventive Breast Self-Care Practices*

Thirty-six point five percent (n:57) of the women included in the research sample stated that they performed BSE regularly every month, 30.8 % (n:48) of them performed it several times in a year and 3.8 % of them (n:6) performed it once a month (any day of the month). Twenty-three point seven percent (n:37) of the women stated that they undergone the clinical breast examination once a year, 9.6% (n:15) of them stated that they took it once every two years and 66.7 % of them (n:104) expressed that they had never undergone the clinical breast examination. Besides, 37.2% (n:58) of the women included in the research sample stated that they took mammography once a year, 6.4% of them (n:10) took it once every two years, 1.3% of them (n:2) took it once every six months and 55.1% (n:86) of the participants specified that they had never taken the mammography screening.

## **Discussion**

In this research, information and support needs of women having breast cancer in the first degree relatives and to what extent these needs were met were indicated. The information need item placed at the top by the women included in the research sample as very important was “information about the treatments of breast cancer”. The other items found important by them were “information concerning the reasons of breast cancer”, “possible risk factors of breast cancer”, and “information and demonstration of breast self-examination”.

Items specified as very important by most of the women showed similarity with the literature. Items indicated as very important by women in the descriptive studies that Chalmers et al. conducted in 2003 in Canada (n:261) and Tunin et al. carried out in 2010 in Israel (n:128) through the same scale were items related to the information on the BSE, clinical breast examination, mammography screening, being at risk of having breast cancer and the reasons of breast cancer (Chalmers et al., 2003; Tunin et al., 2010). It was found in the studies carried out on the women having breast cancer in their first degree relatives that they wanted to receive information mainly about the new development in the screening and treatment of breast/ovary cancer (Stacey, 2002; Iredale et al., 2003),

risk of breast cancer, lifestyle change alternatives for lower risk (Stacey et al., 2002; Sinicrope et al., 2009), HRT, protection with medicine and side effects (Stacey et al, 2002; Iredale et al, 2003), performing BSE, taking the clinical breast examination and mammography, new developments in genetics (Iredale et al; 2003). Results of our research indicated that women at high risk in our country paid importance to the disease and its treatment as well as protection from it and early detection practices but they attached more importance to the information regarding the treatment. This was attributed to the “vital” characteristic of this information (Chalmers et al; 2003).

The first three items specified by women as very important among the support need items were “having a knowledgeable health professional to watch me performing breast self-examination and to check whether I am doing it properly”, “having support to help me develop a ‘plan’ if I have breast cancer” ( $\bar{x}$ :3.70±0.45) and “having support to help me carry out breast self-examination on a regular basis” ( $\bar{x}$ :3.44±0.82). Order of importance of the support needs of women included in our research was found similar to the other studies (Chalmers et al., 2003; Tunin et al., 2010).

Most women in this study did not meet the recommended conditions for BSE, clinical breast examination and mammography screening. While one third of the women (n:52, 33.3 %) took the clinical breast examination, two third (n:104, 66.7%) stated that they had never taken it. At the same time, almost half of them (n:70, 44.9%) took the mammography screening while more than half of them (n:86, 55.1%) had never taken the mammography screening. While one third of the women (n:57, 36.5%) performed BSE regularly every month, almost one third of them (n:41, 26.3%) did not take it at all. The ratio of women to perform BSE regularly was found similar to the ratio of women having breast cancer in the first degree relatives to perform BSE in the literature (Chalmers et al, 2003; Cohen, 2006). In the literature, the ratio of women having breast cancer in the first degree relatives to perform BSE varies between 10-40%, their ratio to take the clinical breast examination varies between 9-35% and their ratio to take mammography screening varies between 8-40% (Chalmers et al., 2003; Norman and Brain, 2006; Cohen, 2006; Sinicrope et al., 2009; Rees and Bath, 2000). However, different results were shown in terms of the early detection practices of women having breast cancer in their first degree relatives (Chalmers and Thomson, 1996; Rees and Bath, 2000; Norman and Brain, 2006). It was determined in the study conducted by Chalmers et al. in 2003 that 39.8% of the women performed BSE regularly every month. Women had difficulty in adapting to the early detection practices while they were worried about the health of their relatives with breast cancer (Chalmers and Thomson, 1996). It was also shown in the study conducted by Norman and Brain in 2005 that women having breast cancer in the family history performed BSE irregularly. It was found that risk perceptions of women experiencing breast cancer within the family caused anxiety. As shown by Chalmers and Tahomson in their articles, high cancer anxiety can result in either performing the BSE frequently or refraining from it (Chalmers & Thomson, 1996). On

the other hand, no difference found in another study between women having breast cancer within the family and those not having breast cancer in the family history in adapting to the early detection practices (Chalmers et al., 2003). Furthermore, it was found in the study conducted by Cohen in 2006 that women having breast cancer in the family history had higher ratios to perform the BSE regularly than the women not having breast cancer in the family history. It was also determined explored that most of the women did not take the clinical breast examination and mammography screening. Likewise, it was found that most of the women aged 40 and below with a breast cancer case in the family history had never taken the clinical breast examination and mammography screening and the ratios of women with and without a breast cancer case in the family history to take the clinical breast examination were found to be similar (Cohen, 2006). The low ratio of women included in our research sample to perform BSE may be explained by that a health professional is needed while learning and performing the BSE, women do not consider themselves as competent, they fear to diagnose breast cancer and to detect a tumor. Explaining the aims of BSE to the women and demonstrating how to perform it on a breast model may increase the adaptation to BSE.

Information need item specified by the women participating in our research as met fully in the first place was "information about the treatments of breast cancer". At the same time, women stated that the item of "information about how to talk with my children about their possible risks for breast cancer" was not met at all. The other items specified by the women as not met were information "information about how to talk with my family about my risk for breast cancer" and "information about genetic counselling for myself and my children". Ranking of the degrees to which the information needs of the women were met was found to be similar with the other studies 23, 27. The result that the information needs of women as regards to how to talk with their family about their own and their children's risks for breast cancer and genetic counselling were not met caused us to conclude that health professional mainly gave information about the disease and its treatment and did not give information concerning the communication between patient and family. This result may also be explained by that such issues as communication within the family are not priorities of the health professionals and that these issues are not considered as primary problems. The fact that the genetic counselling is limited in Turkey is thought to effect this result.

It was detected explored in this research that almost one third of the participants (n:44, 28.2%) specified their source of information as "oncologist". However, only three of them (1.9%) stated as "nurse". Besides, it was determined that half of the (n:78, 50%) women included in the research wanted to get information from "oncologist" while only eight women (5.1%) wanted to get from "nurse". The result that only three women specified nurses as sources of information made us think that women did not consider nurses as source of information. Breast care nurses work in many countries throughout the world such as Australia, Ireland, America and provide information and

support to the patients and their relatives in every phase of the disease from diagnosis to rehabilitation (Jiwa 2010, Eicher 2006, EONS 2009). However, in Turkey, there are neither breast care nurses providing counselling, giving information and support during the whole treatment process beginning from the diagnosis phase nor the certificate programs to train breast care nurses. Thus, patients and relatives receive information and support from nurses working in different units including general surgery, radiotherapy and chemotherapy. The fact that nurses were not specified as source of information in our research may be attributed to that nurses working in these units receive training in a limited time due to overcrowding patients as these nurses provide service to all cancer patients and they can not always allocate the sufficient time to the patient and relatives.

The primary item specified by the women as met fully among the support needs was "having support to help me relieve my anxiety about getting breast cancer". However, the first three support needs specified by the women as not met at all were firstly, "having a group to attend for support" and "reminders for mammography appointments", secondly "reminders for breast cancer self-examinations" and thirdly "having a knowledgeable health professional watch me performing the breast self-examination and check whether I am doing it properly". These results were different from the results of other studies (Chalmers et al., 2003, Tunin et al., 2010). Unavailability of reminders for mammography appointments and BSE of women in the health system of Turkey was thought to cause these needs to remain unmet.

Ranking of the degrees to which the support needs were met was found similar with the other studies. In the qualitative study conducted by Iradale et al. in England in 2003, it was reported that women had support needs and support groups were specified as appropriate alternatives in order to provide emotional support. However, almost one fifth (n:30, 19.2%) of the women participating in our research determined that they wanted to receive support from "support groups/volunteers". Some found that they wanted to receive support primarily from nurses even though they received support from their "families". In a study, it was shown that sources that women having breast cancer and their families received support were usually health professionals (surgeon, family doctor, oncologist, breast nurse etc.) (Davis et al., 2004). The fact that "family" was considered as a source of support in this research was thought to result from cultural characteristics of the Turkish culture related to the family such as living together, solidarity within the family and strong family relationships. The fact that nurses came first in the ranking of desired sources of support but were ranked number four among sources that women received support may be attributed to the busy working environment of nurses in our country and lack of time to allocate to the patients. In a study conducted in England, it was demonstrated that breast care nurses met the information needs of women with breast cancer and provided the women and their families with emotional support in the long term follow-up (Carnwell and Baker, 2003). In this context, certificate program should be developed for breast care nurses and

tasks, roles and responsibilities of breast care nurses should be determined.

In conclusion, it was detected in this research that information needs of women were more important than their support needs and their information needs were met at a higher level when compared to their support needs. It was determined that women stated the reasons of the breast cancer, its treatment, its symptoms, BSE and the lifestyle changes to be made to prevent the breast cancer as very important in terms of information needs. The items specified as very important by the women in terms of support needs were learning to perform the breast self examination, their breast cancer anxiety for themselves and their relatives, having their breast examined by a health professional. It was found out that information needs of women regarding the breast cancer treatment, mammography screening and breast cancer risk were met fully. Moreover, it was determined that their information needs as regards to how to talk with their children about the risks carried by both women and children and the genetic counselling for themselves and their children were not met at all. It was also found out that women mainly received information from “oncologist” and they wanted to receive information from “oncologist”. At the same time, they largely received support from their families but they wanted to receive support from “nurses”.

Nurses and the other health professionals should give information to the women having breast cancer in the first degree relatives concerning the breast cancer, its reasons, screening, diagnosis and treatment methods and protection from breast cancer. It is also important that nurses should provide the women having breast cancer in the first degree relatives with support in order to teach them how to perform the breast self-examination and to reduce their anxiety for themselves and their children. Nurses providing support to the patient should also provide support to the family. Mammography appointments and BSEs should be reminded to the women. Breast care nursing roles should be determined in Turkey and certificate programs should be developed for breast care nursing. Furthermore, interventional studies aimed at unmet information and support needs of women should be planned and the effectiveness of the intervention should be evaluated.

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