INFORMATION AND SUPPORT NEEDS OF WOMEN WITH PRIMARY RELATIVES WITH BREAST CANCER

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MEME KANSERİ OLAN BİREYLERİN BİRİNCİ DERECE AKRABALARININ BİLGİ VE DESTEK GEREKSİNİMLERİ

ÖZET

Amaç: İki aşamada gerçekleştirilen araştırmanın; birinci aşaması; Chalmers ve Thomson (1996) tarafından geliştirilmiş Information and Support Needs Questionnaire (Bilgi ve Destek Gereksinimleri Ölçegi)'nin geçerlik ve güvenirliğini değerlendirmek amacıyla metodolojik, ikinci aşaması; meme kanseri olan bireylerin birinci derece akrabalarının bilgi ve destek gereksinimlerini belirlemek amacıyla tanımlayıcı olarak gerçekleştirilmiştir.

Hastalar ve Yöntem: Birinci aşamada ölçeğin geçerlik ve güvenirliğini saptamak için 10.06.2005-15.02.2006 tarihleri arasında Ege Üniversitesi Meme Polikliniği ve Radyasyon Onkolojisi bölümlerine başvuran meme kanserli bireylerin birinci derece akrabaları ile görüşülmüştür (n=100). İkinci aşamada, 01.03.2006–15.05.2006 tarihleri arasında, aynı yerde, ilk çalışma kapsamına alınmayan meme kanserli bireylerin birinci derece akrabaları ile görüşülmüştür (n=150).

Bulgular: Ölçeğin Kendall iyi Uyuşum Katsayısı W: 0.244 ve p<0.01 olarak; birinci ve ikinci uygulama arasındaki test-tekrar test güvenirlik katsayısı bilgi gereksinimi r=0.99, destek gereksinimi r=0.99 olarak yüksek düzeyde bulunmuştur. Ölçeğin zamansal süreçteki tutarlılığının yeterli düzeyde olduğu belirlenmiştir (p=0.00). Ölçeğin birinci uygulamasında Cronbach alpha katsayısı bilgi gereksinimleri için 0.87, destek gereksinimleri için 0.91; ikinci uygulamasında sırasıyla 0.85, 0.90 olarak saptanmış ve ölçeğin güvenirliği yüksek bulunmuştur (0.80<α<1.00). Geçerliği ve güvenilirliği araştırmanın birinci bölümünde saptanan ölçeğin uygulaması sonucunda, birinci derece akrabası meme kanseri olan kadınların özellikle bilgi gereksinim puan ortalamalarının yüksek olduğu saptanmıştır (destek gereksinimi, X=1.98±0.97, bilgi gereksinimi, X=3.46±0.29).

Sonuç: Bilgi ve Destek Gereksinimleri Ölçeği Türk kadınları için geçerlik ve güvenirliğini olan bir ölçektir. Kadınların bilgi gereksiniminin destek gereksiniminden daha yüksektir. Ölçeğin birinci derece akrabası meme kanseri olan kadınlara uygulanması verilecek hizmetlere yol gösterici olabilir.

Anahtar sözcükler: meme kanseri, bilgi, destek, ihtiyaç, ölçek

ABSTRACT

Purpose: The research was conducted in two stages; the first stage was carried out methodologically to assess the validity and reliability of the Information and Support Needs Questionnaire developed by Chalmers and Thomson (1996). Second stage was conducted descriptively to determine the information and support needs.

Patients and Methods: The validity and reliability of the scale an interview was conducted with the first-degree relatives of individuals with breast cancer who referred to Breast and Radiation Oncology Department of Ege University (n=100) in 10 June 2005-15 Feb. 2006. The second stage of the research was carried out at same departments between the dates of 01 March - 15 May 2006 (n=150).

Results: The Kendall Compatibility Coefficient of the scale was found as W: 0.244 and p<0.01. Test-retest reliability coefficient information and support needs and between the first and second applications were found as r=0.99. It was established that the consistency of scale at temporal stage was at a sufficient level. Cronbach alpha coefficient information need was found 0.87 and support need 0.91; they were found 0.85 and 0.90 respectively. The reliability of the scale was found high (0.80<α< 1.00). As a result of application of the scale which its validity and reliability were determined in the first section the mean scores especially of information needs of the women who has a first-degree with cancer were found high (X =1.98±0.97 for support need and X =3.46±0.29 for information need).

Conclusion: Women's information need was found higher than their support need.

Key words: breast cancer, information, support, need, scale

Introduction

Breast cancer is the development of breast cancer in the family, the degree of the relationship to the women women with breast cancer, family history of breast cancer in first degree relatives and

emphasizes the importance of age at emergence (1, 2). Therefore, especially in first degree relatives such as mothers and sisters of women with a history of breast cancer, much more than those without risk factors should be closely monitored and observed

(3,4). women who have breast cancer in their families can live in fear and anxiety, and are adversely affected by reflecting on this, so the diagnosis of breast cancer is emphasized as a family disease (5,6). Therefore, first-degree relatives of breast cancer patients share their experiences with breast cancer patients and they themselves are considered at risk (5,7). Rees and Bath expressed that correct perception of individual risk and compliance practices, and early diagnosis is effective in reducing the fears and anxiety (5,6). Thus, first-degree relatives of patients with breast cancer must be identified so their needs can be met through information, education and support. (3).

In our country, studies have generally examined the needs of individuals with breast cancer (2) or the education given to women with breast cancer (7), but the genetic aspects of the individual's first-degree female relatives with breast cancer risk will determine the needs of the Turkish reliability and validity of a scale used was detected. In this context, the main purpose of the study, women with breast cancer information and support needs of first-degree female relatives to measure developed by Chalmers and Thomson Information and Support Needs Questionnaire to determine the reliability and validity of Turkish version. In addition, this study, the scale included in the study area by the operation of the first-degree relatives of breast cancer in women with breast cancer to determine the needs for the information and support.

Material and Methods

Research type: Two-stage research, the first phase is the Information and Support Needs Questionnaire to assess the validity and reliability of the methodology and the second phase a descriptive study was conducted to determine the information and support needs of the first degree relatives of individuals with breast cancer.

Location of the study, the universe and sample: The data Ege University Department of Breast (DB) and Department of Radiation Oncology (DRO) was carried out by conducting face to face interviews.

The first stage of the study and the example of the methodological part of the universe; 10.04.2005-15.11.2005 DRO between DB and consisted of first-degree relatives of women admitted with a diagnosis of breast cancer. Validity and reliability of the scale used in this study to determine the sample size of the first chapter, on the basis of the number of scale items, item number at least three times the number of samples is planned to be taken. In this direction, scale, 29 items of the scale is the Turkish version of the planned implementation of at least 87 people, who agreed to participate in research study at the end of the scale, was applied to 100 people.

The second phase of the study tested the validity and reliability of the Information and Support Needs Questionnaire field application was carried out between 01.12.2006-15.05.2006. Between
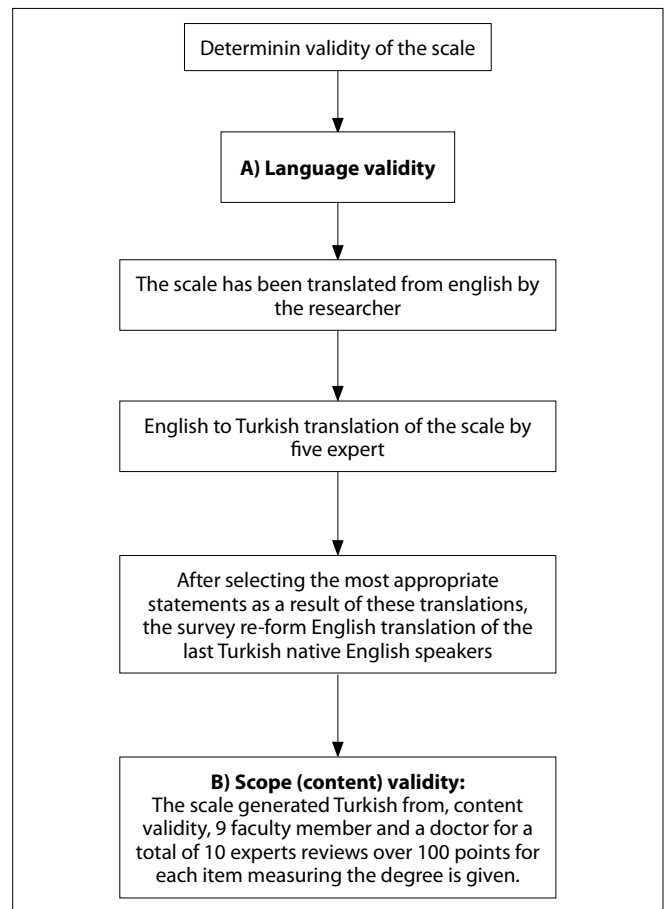

Figure 1. "First-degree relatives of individuals with breast cancer information and support needs scale" run of the validity of the flow chart

these dates, question forms the DB and DRO are first-degree female relatives of women with breast cancer admitted to the center of all of the applied sampling only since.

Data collection: Data collection of socio-demographic features of women by a questionnaire consisting of 37 questions and "First-degree relatives of individuals with breast cancer information and support needs scale" was used in two forms. Data collection phase took 13 months.

First-degree relatives of individuals with breast cancer information and support on the scale of needs; In 1996, Chalmers and Thomson (8) and developed by the work done by researchers with the same 2001 (9), and in 2003 (10) re-arranged. Breast cancer information and support needs of individuals including relatives of the scale consist of 29 items. Likert-type scaling method was used in the scale. 4 'ranging from"0" (the most important (4), important (3), somewhat important (2), junk (1), is not suitable (0) ratings are based on the information requirements, the results are evaluated. Support the requirements to be met, ranging from"0" from the"4"to (completely (4), fairly (3), little (2), no (1), is not suitable (0) ratings are based on the results evaluated.

Evaluation of data: first-degree relatives of breast cancer information and support needs of individuals used for the validity of the scale (Figure 1) and reliability (Figure 2) to operate on the flow chart of the operations is given. For the computer analysis of data obtained from the research Statistical Package for Social Science (SPSS) was 13.0 package programs.

Determining the validity of the scale: Language validity, the study used 'Information and Support Needs Scale' for the adaptation of the Turkish community in the first phase of research is to test the validity of the scale was carried out in studies on the validity of the language. First, the scale has been translated from English by the researcher. Then, who knows the scale of the two languages (Turkish, English), four experts have been translated from English by a faculty member and an expert physician. After selecting the most appropriate statements as a result of these translations, the survey re-form English translation of the last Turkish native English speakers and providing education in both languages were made by an expert. First degree relatives of individuals with back translation of Breast Cancer-Specific Information and Support Needs Questionnaire made the necessary corrections in comparison with the original scale and the scale was finalized.

Scope (content) validity, the scale generated Turkish form, content validity, 9 faculty members and by a doctor for a total of 10 experts reviews over 100 points for each item measuring the degree is given. Kendall Coefficient of Concordance (W) was used to make the terms more understandable.s; the scale a result of recommendations made by the experts was finalized.

The scale reliability determination: the scale, the reliability determination, test-retest reliability, Pearson's Product Moment Correlation technique, internal consistency 'Cronbach's Alpha Analysis', 'Total Score Correlation technique ", Two Half Test Reliability ", Guttman Splitt-half 'and the' Spearman-Brown reliability coefficients were used.

Ethics in research: During the planning stage of the research, Ege University Izmir Ataturk School of Health Research Committee, Consultation and approval from the ethics committee, for the conduct of the Faculty, the official was allowed. The aim of the research provides information about women in the study, volunteers participated in and received verbal permission.

Results

Validity and reliability of the women in work (n = 100) were 15% of the 35-39 age group, the mean age was 14.63 ± 38.29 (min: 15, max: 70), 57% were married, 56% of the high school graduates, 60% work, 41% were housewives. 49% of the income levels of women at expense of income as stated. 71% and 43% of women with breast cancer in the child's mother was found to be relatives.

Findings concerning the validity of the scale: Content validity of ten experts consulted for the 'Information and Support Needs
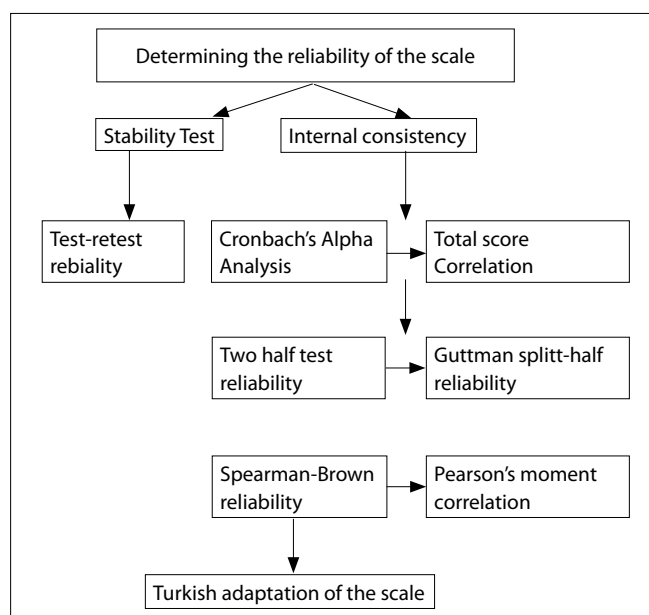

Figure 2. "First-degree relatives of individuals with breast cancer information and support needs scale" run of the reliability of the flow chart.

Questionnaire ' items from the lowest and the highest scores and the mean scores of items were examined in the average score of expert opinions, the lowest average score of 20th item (Reminders for breast self-examinations (ie, sent out in the mail or by telephone) (X = 77 ± 7.29), the highest average score in the 14th substance (information about possible risk factors in breast cancer (eg, oil-rich diet, such as hormone replacement therapy) (X = 99 ± 3.16), respectively. Kendall Coefficient of Concordance analysis of the expert opinion of a good harmonization W: 0244 and p <0.01 was obtained.

The findings concerning the reliability of the scale: Information and Support Needs Questionnaire between the first and second applications of the test-retest reliability coefficient of r = 0.99 the need for information, support requirement r = 0.99, respectively (Table 1). Information and Support Needs Questionnaire temporal consistency of the process were significantly (p = 0.00).

Information and Support Needs Questionnaire for both the first and second applications, information and support needs of high-level Guttman Split-half, Spearman-Brown reliability Cronbach's

Table 1. 'Information and Support Needs Scale test-retest reliability Result

Test-retest Applications	n	IN		SN	
		r	p	r	p
1st **Applications**	100				
2nd. **Applications**	100	0.99	0.00	0.99	0.00

IN: Information Needs - SN: Support Needs
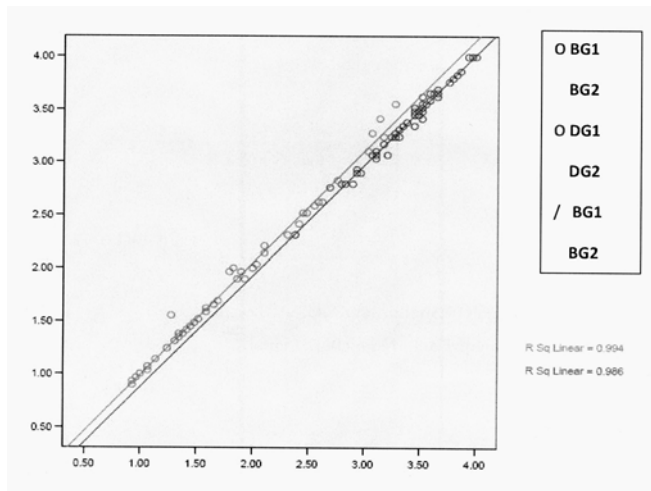
Graphic 1. 'Information and Support Needs Scale Correlation Chart of the First and Second Application Article.

alpha and correlation coefficients were obtained. Information and Support Needs Questionnaire consistent with each other in terms of two halves of the information and support needs and high reliability was found to be separate. First practice, Guttman split-half reliability coefficient of 0.75 need for information, support requirement 0.84, the correlation between two semi-information requirement 0.60, 0.78 need for support, information need of the Spearman-Brown reliability coefficient of 0.75, 0.87 support requirement, 15-point first-half Cronbach alpha value of the information requirement 0.75, 0.84 and 14-item 2 support is needed Cronbach alpha value of 0.84 part requirement information, support requirement was found to be 0.88.

Information and Support Needs Questionnaire Cronbach's alpha coefficient was calculated for the Likert-type scale. Information and Support Needs Questionnaire 0.87 for the first practice, Cronbach alpha coefficient information requirements, support requirements, 0.91, 0.85 for the second application, information requirements, support requirements were found to be 0.90. Accordingly, first-degree relatives of individuals with breast cancer-specific Information and Support Needs Questionnaire reliability levels were high (0.80 ≤ α <1.00).

Findings about the scale internal consistency: First-degree relatives of women with breast cancer, Information and Support Needs Scale each of the twenty-nine-item scale mean when an item and item-total correlations and alpha values, the first application of scale items (Information Needs Alpha = 0.85, Support Needs Alpha = 0.90) and the second application (Information Needs Alpha = 0.87, Support Needs Alpha = 0.91) were evaluated for the first and second application was a relationship between (Graphic 1).

First-Degree Relative with Breast Cancer Information and Support Needs of Women on the average score Results: The

first phase of the study, Information and Support Needs Scale for Turkish women, after the second stage, the validity and reliability of the scale, first-degree relatives of women with breast cancer in another group (150) were applied. 14% of the women were aged 40-44, mean age was 38.59 ± 14.50 (min: 15, max: 76), 59.4% third of married, 32.7% 'of them are high school graduates, 56%, 7 of them working, 38% were housewives. Women expressed that 64% of the income status of women 'income equivalent to expenses as and 72.7% of children expressed. 43.3% of the women third of his mother, 34.7% of them are sister's breast cancer, their relatives put the average duration of breast cancer diagnosis was 31.26±35.89 months. Women 62.7% of relatives of breast cancer are considered a risk to himself, while 32.7% percent stated that he did not know whether there is risk.

Table 2 shows the distribution of the mean scores of these women need to learn. Information and Support Needs Questionnaire validity and reliability study tailored to the post of Turkish women in the highest average scale score ($X^2 = 3.78 \pm 0.41$) 21 times ('regular examinations of my breasts by a knowledgeable health professional (ie, physician, nurse, etc)) seems to have. The lowest average score of the scale, the need for information is (X = 2.90 ± 1.64) item 9 ('Information about my daughter's risk for breast cancer'), and 10th item (X = 2.90 ±1.64) (' Information about how to talk with my children about their possible risks for breast cancer'), respectively. The mean total score of information needs was the X = 3.46 ± 00:29. First-degree relatives of women with breast cancer need to support the distribution of scores is examined, the average total score of the support requirement was found to be X = 1.98 ± 0.97. Support the need for the highest mean score (X = 1.78 ± 3.55) 13th item (' Information about how to support my relative during her experience with breast cancer ') were determined. The lowest score on the need for support in the ($X^2 = 1.40 \pm 1.10$) 9th item ('Information about my daughter's risk for breast cancer') were determined.

Discussion and Conclusions

The first phase of this study, 'Information and Support Needs Scale for Turkish women as a result of the implementation of the validity and reliability of this scale was high, and the need for information was high for first-degree relatives of women with breast cancer..

Validity, reliability of the scale is applied to women's characteristics; Chalmers (10) compared with the reliability and validity studies carried out by women, mean age, marital status and having children to each other in a similar situation, in terms of education and income level were found to be different from each other. In this situation our country and the UK's socio-cultural, socio-economic structure is thought to be due to differences..

A scale was developed in a different country, another culture is not sufficient to use the translation of one language into another language. At this stage, evaluation and analysis are needed in many (11, 12). As a result, first-degree relatives of women with breast

Table 2. Breast Cancer Information Needs of Women With First-Degree Relative Distribution of Scores

Items	Information Needs n=150		Support Needs n=150	
	Ort.	**S.S**	**Ort.**	**S.S**
1. Information on how to talk with my relative about her experience with breast cancer	3,72	0,44	1,98	1,19
2. Information about what causes breast cancer	3,63	0,48	1,95	0,99
3. Information about the treatments for breast cancer (eg, radiation, chemotherapy, side effects, etc)	3,56	0,61	1,76	0,93
4. Information about the emotional reactions of women who are newly diagnosed with breast cancer	3,46	0,59	1,70	0,93
5. Information about the emotional reactions and physical symptoms of women who are undergoing treatment for breast cancer	3,55	0,49	1,76	0,97
6. Information about how to talk with my family (spouse/partner, children, siblings, etc) about my relative's experience with breast cancer	3,41	0,65	1,80	1,01
7. Information about my own personal risk for breast cancer	3,52	0,62	1,88	1,01
8. Information about how to talk with my family about my risk for breast cancer	3,58	0,49	1,75	0,97
9. Information about my daughter's risk for breast cancer	2,90	1,64	1,40	1,10
10. Information about how to talk with my children about their possible risks for breast cancer	2,90	1,64	1,53	0,95
11. Information about changes in my health habits that might lower my risk for breast cancer	3,70	0,45	1,84	0,99
12. Information about ways I can help to decrease my relative's suffering from breast cancer	3,58	0,49	1,92	0,98
13. Information about how to support my relative during her experience with breast cancer	3,68	0,46	1,98	0,97
14. Information about possible risk factors for breast cancer (eg, high-fat diet, hormone replacement therapy, etc)	3,68	0,46	1,87	0,92
15. Information and demonstration of breast self-examination	3,58	0,49	1,82	0,92
16. Information about mammography screening (ie, how often I should be screened)	3,52	0,50	1,74	0,95
17. Information about how to change my behavior to promote my health	3,42	0,68	1,64	0,79
18. Information about genetic counseling for myself and my children	3,49	0,50	1,60	0,83
19. Reminders for mammography appointments (ie, sent out in the mail or by telephone)	3,40	0,75	1,60	0,85
20. Reminders for breast self-examinations (ie, sent out in the mail or by telephone)	3,42	0,49	1,48	0,80
21. Regular examinations of my breasts by a knowledgeable health professional (ie, physician, nurse, etc)	3,78	0,41	1,71	0,97
22. Support to help me carry out breast self-examination on a regular basis	3,49	0,50	1,58	0,86
23. Support to help me deal with my worries about my relative's illness	3,53	0,50	1,65	0,83
24. Have a knowledgeable health professional watch me do breast self-examination and check whether I am doing it properly	3,49	0,50	1,72	0,86
25. Have someone to talk to about my worries about my relative with breast cancer	3,41	0,49	1,70	0,77
26. Have a group to attend for support	2,98	0,71	1,63	0,74
27. Support to help me ''come to terms'' with my feelings of risk for breast cancer	3,24	0,70	1,56	0,63
28. Support to help develop a ''plan'' if I should get breast cancer	3,36	0,77	1,58	0,66
29. Support to help me decrease my worries about getting breast cancer	3,44	0,49	1,50	0,71
Total	3,46	0,29	1,71	0,61

cancer, Information and Support Needs Questionnaire and expert opinions that the alignment of the scale was found to be valid. As a result of the implementation of two times with 15 days of the scale reliability coefficient is high and the temporal consistency of the process was adequate. Information and Support Needs Scale single-and double the number of items consistent with each other in terms of two half of the information and support needs and high reliability were found to be separate. Cronbach alpha value of the first half for the first practice, the need for information, 0.87, 0.91 for the need for support, 0.85 for the second practice, the need for information, and support for the requirement was 0.90. Similarly, the scale is organized by Chalmers in 2001, the English version of the Cronbach alpha value of 0.92 for the need for information, the support requirement was found to be 0.91. According to the results of the study, Information and Support Needs Scale of substances consistent with each other and the same feature in their completed materials were determined to occur, the scale reliability has a high correlation which was found between the scale items.

The first phase of the study, first-degree relatives of women with breast cancer, Information and Support Needs Questionnaire has the validity and reliability study. The second stage, the scale reliability and validity for Turkish women, another group of first-degree relatives of women with breast cancer (150) wasapplied.

Applied to the scale degrees of kinship between the relatives of women with breast cancer was examined at the highest rate of women (43.3%) of mothers with breast cancer. Similarly, Gençtürk'ün (7) study examined the degree of proximity to the relatives of women with breast cancer in 43.8% of women of the mother's with breast cancer, Chalmers et al. (10) study, 64% of the women in his mother's breast cancer was found. Çay (13) prevention and early diagnosis of cancers unique to women, the study examined the effectiveness of nurses in 55% of women (n = 11) as a result of first-degree relatives of breast cancer supports the findings. To detect breast and cervical cancer risk groups in the Türkdemir's study 27.5% of women's of first-degree relatives of patients with cancer and cancer in 6.2% of them was found to be breast cancer (14).

All first-degree relatives of women with breast cancer are at risk for breast cancer and this is important for these women. Although the average age of women at risk for breast cancer under the age of 50 is considered (38.59 ± 14:50) the women in the group of genetically high risk of breast cancer, should not ignore breast

cancer information and support.t (2, 15, 16). 62.7% of women, patients with breast cancer in a family that considers itself to be a risk for the development of breast cancer in the study. Similarly, Chalmers (8) first-degree relative of a study of women with breast cancer, 41% stated that they saw themselves very much at risk. Chalmers and Thomson (9) in another study, first-degree relatives of women with breast cancer patients dealing with breast cancer; they also feel that they are at risk for breast cancer and trying to look for information on breast cancer said. The researchers, the risk of breast cancer in women, they see themselves informed about the disease, with cases of individual control and would still feel fear, says the lower level (2).

First-degree relatives of the study, 150 women with breast cancer 'Information and Support Needs Questionnaire' was applied. The highest score for the scale, the need for information and support '4 'information needs to be given the average score of women (X = 3.46 ± 0.29) higher mean score in the need for support (X = 1.71 ± 0.61) were significantly lower. The scale is applied to different groups support the information needs of women is higher than the stated requirements (9,10). This information will be developed for first-degree relatives of women with breast cancer need to show that programs will help (2.5).

Most women need breast cancer information and support the need for breast examination. Relatives of those with breast cancer disease would like to talk about their experiences and how they could reduce their risk of breast cancer utilizinf information about changes in health habits. Chalmers, the most important information and support needs of women in the individual risk of breast cancer, breast cancer risk factors, early diagnostic methods, and noted that information on health habits that can reduce the risk of breast cancer (9,10). Sources, the emotional pain of breast cancer in women at high risk require genetic counseling, information about the prevention and detection of breast cancer, and emotional support (expressing their feelings, ensure that the specific strategies for managing stress, talking with women that are similar). coping with the loss of family members with breast cancer can mean psychological and genetic counseling to help with their decision-making is seen as helpful support. (2,17,18,19). First-degree relatives of breast cancer are women who desire education programs so they can be prepared to give priority to the issues that will be significant.

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