



# Fear of Cancer Recurrence in Women with Breast Cancer: A Cross-Sectional Study after Mastectomy

## Meme Kanserli Kadınlarda Kanserin Nüksetme Korkusu: Mastektomi Sonrası Kesitsel Bir Çalışma

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### Abstract

**Aim:** The aim of this study was to determine the fear of cancer recurrence in women with breast cancer after mastectomy.

**Material and Methods:** Data were collected between March and September 2021 with the Personal Information Form and the Fear of Cancer Recurrence Inventory via social media. The sample consisted of 127 women with breast cancer, who were registered in the general surgery service of a training and research hospital in Turkey, could be reached by phone and had a social media account. Descriptive statistics, independent groups t test, One-Way ANOVA and Mann-Whitney U test analysis were used in the analysis of the data.

**Results:** It was determined that the Fear of Cancer Recurrence Inventory mean score was 126.12±24.88 and the coping strategies sub-dimension mean score was 30.96±6.00. It was determined that there was a significant difference between the mean score of the Fear of Cancer Recurrence Inventory and the duration of diagnosis, the status of receiving radiotherapy and chemotherapy, the status of experiencing treatment-related side effects, and the status of doing any sports/exercise ( $p<0.05$ ). It was also determined that the average score of Fear of Cancer Recurrence Inventory was higher in women who did not receive radiotherapy and chemotherapy, did not experience treatment-related side effects, and did not do sports/exercise, between 1-12 months of diagnosis time ( $p<0.05$ ).

**Conclusion:** Health professionals should evaluate the concerns of women with breast cancer and their families about fear of cancer recurrence and help them develop strategies to support their coping.

**Keywords:** Breast cancer, mastectomy, woman, fear of cancer recurrence

### Öz

**Amaç:** Bu çalışmanın amacı meme kanserli kadınlarda mastektomi sonrası kanserin nüksetme korkusunu belirlemektir.

**Materyal ve Metot:** Tanımlayıcı ve kesitsel tipteki bu çalışmanın verileri, Kişisel Bilgi Formu ve Kanserin Nüksetme Korkusu Envanteri ile Mart-Eylül 2021 tarihleri arasında sosyal medya aracılığıyla toplanmıştır. Araştırmanın örneklemini, Türkiye'de bir eğitim ve araştırma hastanesinin genel cerrahi servisine kayıtlı, telefonla ulaşılabilen ve sosyal medya hesabı olan 127 meme kanserli kadın oluşturmuştur. Verilerin analizinde tanımlayıcı istatistikler, bağımsız gruplarda t testi, One-Way ANOVA ve Mann-Whitney U testi analizi kullanılmıştır.

**Bulgular:** Araştırmada Kanserin Nüksetme Korkusu Envanteri puan ortalamasının 126.12±24.88 ve baş etme stratejileri alt boyutu puan ortalamasının 30.96±6.00 olduğu belirlendi. Kanserin Nüksetme Korkusu Envanteri puan ortalamaları ile tanı süresi, radyoterapi ve kemoterapi alma durumu, tedaviye bağlı yan etki yaşama durumu ve herhangi bir spor/egzersiz yapma durumu arasında anlamlı fark olduğu tespit edildi ( $p<0.05$ ). Radyoterapi ve kemoterapi almayan, tedaviye bağlı yan etki yaşamayan, spor/egzersiz yapmayan ve tanı süresi 1-12 ay arasında olan kadınlarda Kanserin Nüksetme Korkusu Envanteri puan ortalamasının daha yüksek olduğu bulundu ( $p<0.05$ ).

**Sonuç:** Sağlık profesyonelleri meme kanserli kadınların ve ailelerinin kanserin nüksetme korkusuyla ilgili endişelerini değerlendirmeli ve baş etmelerini destekleyecek stratejiler geliştirmelerine yardımcı olmalıdır.

**Anahtar Kelimeler:** Meme kanseri, mastektomi, kadın, kanserin nüksetme korkusu

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## INTRODUCTION

Every year, millions of individuals are diagnosed with cancer (1) and breast cancer is the most common type of cancer in females (2,3). According to Globocan 2020 data published by the International Agency for Research on Cancer (IARC), worldwide, there were 19.3 million cancer cases in 2020, 11.7% of which were recently diagnosed breast cancer cases (4). With 43%, breast cancer ranks first among all cancer types observed in women in Turkey and is seen in 1 out of every 4 women (3). Although breast cancer is very common in women, treatment outcomes can be improved and mortality can be reduced, if it is detected early. Breast cancer can be diagnosed in a short span of time with some early detection and screening methods and treatment can be started in the early period (5,6). It is known that breast cancer survival increases with regular use of early detection and screening methods, and timely and effective treatment opportunities in developed countries (7,8). Psychological problems such as anxiety, depression, irritability, uncertainty about the future, pessimism, helplessness, fear of cancer recurrence, decrease in self-esteem, deterioration of body image and fear of death are observed during the process of diagnosis and treatment of the disease (9).

Fear of Cancer Recurrence (FCR) is defined by women who are diagnosed with breast cancer as "feelings of fear, distress or anxiety stemming from the thought that cancer will return or progress" (10-12). According to studies, FCR is related to the negative perception of the disease, low level social support, thinking of the worst-case scenario, high level of anxiety or stress (13-16), which may adversely affect patients' coping skills, future plans, ability to re-adjust to their lives before the onset of the disease and quality of life (17). The perception of cancer as a life-threatening disease is one of the biggest factors that causes FCR which is defined as the concern that cancer may return or progress in the same part of the body or in another part of the body (9). Cancer patients experiencing FCR express their thoughts in the following manner: "Am I likely to be treated again? If so, will I be able to cope with the side effects? Will I become more dependent on others this time? Will I feel lot of pain and suffer? If it repeats or progresses again, will I die?" (18). When the fear of cancer recurrence increases, it adversely affects patients' ability to seek treatment, their approaches regarding problems and way of coping, problem-solving capacity, self-perceptions, perceptions about their environment and the disease, self-worth and self-esteem, anxiety and anxiety levels, work attendance and quality of life (19). The importance of an individual approach in helping cancer patients better cope with the FCR was emphasized in literature (9,20,21). Identifying patients' FCR status and supporting patients in its management are important elements in providing health care. Many factors need to be addressed in FCR management in cancer patients such as identifying and reducing the degree of anxiety and fear, supporting patients to undertake daily activities and regulating the confusion of roles (22). It is important for nurses to provide

a post-treatment FCR evaluation for women diagnosed with breast cancer, to identify associated factors, and to teach and help develop appropriate coping strategies against these fears. Limited number of studies on FCR in women with breast cancer in the international literature (9,11,14,16,20,21) and lack of studies on this subject in the national literature make this research distinctive.

### Study questions

1. What is the level of FCR in women with breast cancer after mastectomy?
2. What are the associated factors affecting FCR in women with breast cancer after mastectomy?

## MATERIAL AND METHOD

This descriptive and cross-sectional study aimed to determine the FCR experienced by women with breast cancer after mastectomy.

The study was conducted with women with breast cancer who were registered in the general surgery service of a training and research hospital in Turkey. After obtaining the necessary ethical committee approval and institutional permissions, women with breast cancer were contacted by phone.

The universe of the study was composed of all the women with breast cancer registered in the general surgery service of the training and research hospital in Turkey where the study was conducted. Considering that the rate of FCR in women with breast cancer is 36% (23) in the literature, 127 women with breast cancer were included in the study with a 5% margin of error and a 95% confidence level ( $Z=1.96$ ), assuming the variability in the population was 0.5 (24).

The inclusion criteria were as follows: (i) older than 18 years (ii) volunteered to participate in the study (iii) had mastectomy (iv) literate (v) able to use a smartphone. The exclusion criteria were as follows: (i) had any psychological problems (ii) refused to participate in the study.

Permission was obtained from the Non-Interventional Clinical Research Ethics Committee of a university in Turkey to conduct the study (Decision No: 2021/188), and it was ensured that the study complied with the principles of Helsinki Declaration. First, women with breast cancer were contacted by phone and given preliminary information about the study. Then, they read the informed consent text included in the link that presented the online questionnaire form and were informed about the purpose and rationale of the study. After reading this information, they replied the following question: "Would you like to participate in the study voluntarily?" with a "yes" or "no". The volunteering women who answered "yes" "filled out the online questionnaire. Women with breast cancer were informed that they could withdraw from the study at any time without giving any reason.

Data were collected between March and September 2021 by sharing the online questionnaire form link created by

the researchers using the URL address "surveey.com" with women with breast cancer via WhatsApp. Personal Information Form and Fear of Cancer Recurrence Inventory were used to collect data.

Personal Information Form; The form, developed by the researchers by examining the relevant literature (20,21,23), consists of a total of 15 questions about the socio-demographic and disease characteristics of women with breast cancer.

Fear of Cancer Recurrence Inventory (FCRI); The inventory was developed by Simard and Savard in 2009 to assess cancer patients' FCR (25). The five-point Likert-type scale consists of 42 items and 7 components: Triggers (Items 1-8), Severity (Items 9-17), Psychological Distress (Items 18-21), Functioning Impairment (Items 22-27), Insight (Items 28-30), Reassurance (Items 31-33), and Coping Strategies (Items 34-42). Scale items are scored between 0-4 and there is no reversed item. The total score obtained from the scale is between 0-168. A high score indicates that increased level of fear of recurrence in patients. The Cronbach-alpha value of the study was calculated as be 0.96 by Eyrenci and Berk (2019) in regards to validity and reliability in Turkey and the Cronbach-alpha value of the present study was found to be 0.84 (26).

### Statistical analysis

Descriptive statistics were used in the study for continuous variables (mean, standard deviation (SD), while frequency distributions were found for categorical variables. Shapiro-Wilk test, histogram and Q-Q graph were used for normality tests. One-way ANOVA, independent groups t-test and Mann-Whitney U test were used to evaluate the difference between socio-demographic characteristics, independent variables, and mean score of FCRI of women with breast cancer. All statistical analyzes were performed in SPSS v21 (IBM Corp., Armonk, NY, USA).  $p < 0.05$  was considered significant.

## RESULTS

Descriptive characteristics of women with breast cancer showed that the mean age of participants was  $50.25 \pm 10.69$  years, 73.2% were married and had children, 38.6% had a university or higher-level degree, 63.0% were unemployed and 91.3% had social security. Of these women, 42.5% had a diagnosis period of 2-5 years, 72.4% received chemotherapy, 45.7% received radiotherapy, 68.5% experienced treatment-related side effects, 65.4% used medication, 46.5% had another chronic disease and 67.7% of them were not engaged in any sports/exercise (Table 1).

When the difference between the mean/median scores of the FCRI was examined according to the descriptive characteristics of women, a significant difference was found between the FCR and the duration of diagnosis, receiving radiotherapy and chemotherapy, treatment-related side effects, and doing sports/exercise ( $p < 0.05$ ).

The result of the post-hoc analysis showed that the

difference in the diagnosis period was caused by those between 1-12 months and the mean score of the women in this group was significantly higher than the other two groups ( $p < 0.05$ ). It was determined that those who did not receive radiotherapy and chemotherapy, who did not experience treatment-related side effects, and who did not do any sports/exercise had higher FCRI scores. No statistically significant difference was found between FCRI mean/median scores and age, marital status, having children, education status, employment status, social security status, medication status, and having another chronic disease the of FCRI ( $p > 0.05$ ) (Table 2).

**Table 1. Distributions of descriptive characteristics of women with breast cancer (n=127)**

Descriptive characteristics	n	%
<b>*Age (X±SD) 50.25 ±10.69</b>		
<b>Marital status</b>		
Married	93	73.2
Single	34	26.8
<b>Having child(ren)</b>		
Yes	93	73.2
No	34	26.8
<b>Educational level</b>		
Literate	15	11.8
Primary school	15	11.8
Secondary school	48	37.8
University and above	49	38.6
<b>Employment status</b>		
Working	47	37.0
Not working	80	63.0
<b>Social security</b>		
Yes	116	91.3
No	11	8.7
<b>Duration of diagnosis</b>		
1-12 month	49	38.6
2-5 year	54	42.5
6 year and above	24	18.9
<b>Receiving chemotherapy</b>		
Yes	92	72.4
No	35	27.6
<b>Receiving radiotherapy</b>		
Yes	58	45.7
No	69	54.3
<b>Having an experience of treatment-related side effects</b>		
Yes	87	68.5
No	40	31.5
<b>Medication status</b>		
Yes	83	65.4
No	44	34.6
<b>Having another chronic disease</b>		
Yes	59	46.5
No	68	53.5
<b>Any sport/exercise situation</b>		
Yes	41	32.3
No	86	67.7
<b>Total</b>	<b>127</b>	<b>100.0</b>
*X: Mean; SD: Standart deviation		

**Table 2. Difference in FCRI mean/median scores of women with breast cancer according to their descriptive characteristics**

Variables	n	FCRI		Test	p
		X	SD		
<b>Age</b>					
18-49	70	128.35	24.79	1.121	0.264*
50 and above	57	123.38	24.93		
<b>Marital status</b>					
Married	93	127.76	23.63	1.229	0.221*
Single	34	121.64	27.89		
<b>Having child(ren)</b>					
Yes	93	127.76	23.63	1.229	0.221*
No	34	121.64	27.89		
<b>Educational level</b>					
Literate	15	143.66	25.26	2.756	0.056**
Primary school	15	119.53	36.86		
Secondary school	48	125.64	21.17		
University and above	49	123.24	22.03		
<b>Employment status</b>					
Working	47	125.46	21.79	0.051	0.951*
Not working	80	126.21	26.61		
<b>Social security</b>					
Yes	116	125.29	24.14	-1.227	0.222*
No	11	134.90	31.72		
<b>Duration of diagnosis</b>					
1-12 month (a)	49	135.46	21.66	8.518	0.000**
2-5 year (b)	54	124.00	22.92		
6 year and above (c)	24	111.83	28.15		
					a>b.c
<b>Receiving radiotherapy</b>					
Yes	58	115.65	23.55	-4.697	0.000*
No	69	134.92	22.58		
<b>Having an experience of treatment-related side effects</b>					
Yes	87	121.51	24.31	-3.188	0.002*
No	40	136.15	23.37		
<b>Medication status</b>					
Yes	83	124.48	24.50	-1.023	0.308*
No	44	129.22	25.57		
<b>Having another chronic disease</b>					
Yes	59	123.20	27.17	-1.235	0.219*
No	68	128.66	22.61		
<b>Any sport/exercise situation</b>					
Yes	41	118.34	26.88	-2.484	0.014*
No	86	129.83	23.12		
<b>Receiving chemotherapy</b>		<b>Median</b>	<b>Min Max</b>		
Yes	92	124.0	58-180	961.500	0.000***
No	35	144.0	75-166		

\*t= Independent t test; \*\*F=One-Way ANOVA; \*\*\*U=Mann-Whitney U

The study concluded that the FCRI mean score was 126.12±24.88 for the participating women. In the FCRI, women with breast cancer had a mean score of 24.50±6.31 in the Triggers sub-dimension, 27.84±5.55 in the Severity sub-dimension; 12.53±3.72 in Psychological Distress

sub-dimension; 30.96±6.00 in the Coping Strategies sub-dimension; 15.23±5.82 in the Functioning Impairment sub-dimension, 7.85±3.16 from the Insight sub-dimension and 7.18±2.90 from the Reassurance sub-dimension (Table 3).

**Table 3. FCRI total/sub-dimension mean score of women with breast cancer**

Total FCRI and sub-dimensions	X ± SD	Min-Max
Triggers	24.50 ± 6.31	8.00-40.00
Severity	27.84 ± 5.55	11.00-41.00
Psychological distress	12.53 ± 3.72	4.00-20.00
Coping strategies	30.96 ± 6.00	15.00-44.00
Functioning impairment	15.23 ± 5.82	6.00-30.00
Insight	7.85 ± 3.16	3.00-15.00
Reassurance	7.18 ± 2.90	3.00-15.00
<b>Total FCRI</b>	<b>126.12 ± 24.88</b>	<b>58.00-180.00</b>

## DISCUSSION

This study is significant for the national literature for assessing the FCR levels of women with breast cancer after mastectomy and the relevant factors that affect FCR. In addition, this study demonstrates that FCR remains a cause for concern after mastectomy in women with breast cancer.

For most cancer patients, the end of treatment means living with FCR (27). As a matter of fact, women with breast cancer consider FCR as one of the top five problems (14). Findings from this study demonstrated that women with breast cancer experienced this fear in varying degrees. It was found that the mean FCRI score of women was high after mastectomy. Previous studies conducted with cancer patients and/or breast cancer reported that after treatment, patients experienced FCR in varying degrees, from moderate to high (16,21,28,29). In addition, it was reported that receiving the hormonal therapy after primary treatment and hormonal therapy related-physical symptoms were also considered as signs of recurrence of the disease (21,30,31).

The study found that the coping strategies sub-dimension mean scores were close to high levels. The fact that having different roles such as gender, spouse, parent and employee may affect the ability to cope with FCR (12). Interacting with other breast cancer individuals around women with breast cancer and hearing about relapsing patients may affect their coping skills and cause them to experience FCR (16,32). In addition, inadequacy of the perceived social support mechanisms can lead to a decrease in coping levels and trigger FCR (33,34). The results in this study are similar to those found in the literature, and it can be argued that support by health professionals is important for women so that they can cope with physical symptoms, changing roles and daily life activities after mastectomy without anxiety.

A significant difference was found between the mean/median FCRI score of women with breast cancer and the



duration of diagnosis, the status of receiving radiotherapy and chemotherapy, the side effects of the treatment, and the status of doing any sports/exercise. It was determined that the duration of diagnosis ranging from 1-12 months had higher mean FCRI scores. Previous studies reported that patients with a recent diagnosis period had higher FCR levels (15,28). As the duration of diagnosis increases in women with breast cancer, a decrease in FCR level may be observed because anxiety about recurrence continues (11). This can be explained by the fact that the treatment options of breast cancer are quite advanced, diagnosis can be made at an early stage, the postoperative period is improved, and the life expectancy is longer. In addition, it was reported that the increase in the time elapsed after diagnosis could be related to the development of coping strategies by patients and, accordingly, feeling FCR at lower levels (21).

It was concluded that women who did not receive radiotherapy and chemotherapy, did not experience treatment-related side effects, and did not do any sports/exercise had higher mean/median FCRI scores. Although there is no data in the literature to compare with these results, early diagnosis of breast cancer, application of various treatment methods and high success levels may positively affect patients' beliefs about treatment and FCR (34). At the same time, it is reported that the expected survival rates of patients after breast cancer treatment is higher (35). For this reason, it is believed that women who did not receive radiotherapy and chemotherapy and did not experience any side effects related to treatment had higher FCR. Lifestyle change in patients with breast cancer in addition to medical treatment is accepted as an important treatment strategy (36). It is reported that regular daily physical activity reduces comorbidity in breast cancer patients (37). For instance, it was reported that exercise in patients with breast cancer reduced disease-related inflammation and biomarkers, and improved well-being and quality of life (38). In this context, the study predicts that women with breast cancer who do not do regular exercise/sports may have a high FCR because they cannot maintain a healthy lifestyle change.

### Limitations

This research has some limitations. First of all, the study was carried out online on social media due to the COVID-19 pandemic. Therefore, the data collection process was interrupted. Second, the study was conducted only with women who have breast cancer registered in the general surgery service of a training and research hospital in Turkey. Third, the different disease stages and treatment modalities of women may have affected their FCR differently.

### CONCLUSION

The results of this study demonstrate that FCR is a significant issue for women with breast cancer. Although the severity of FCR may vary, it can continue for a long time after mastectomy, and the coping strategies used

by women with breast cancer may be inadequate. In addition, the women who were recently diagnosed, who did not receive radiotherapy and chemotherapy, who did not experience treatment-related side effects, and who did not exercise/sport had a higher level of FCR. Therefore, healthcare professionals, especially nurses, should understand and assess the concerns of women with breast cancer and their families about FCR. In addition, healthcare professionals should support these women and their families in developing strategies to cope with FCR and should inform them about services that provide psychological support.

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**Ethical approval:** Permission was obtained from the Non-Interventional Clinical Research Ethics Committee of a university in Turkey to conduct the study (Decision No: 2021/188), and it was ensured that the study complied with the principles of Helsinki Declaration.

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