

Determining Healthcare Seeking Behavior, Psychosocial Symptoms, and Distress Levels of Women with Gynecological or Breast Cancer During the COVID-19 Pandemic

Jinekolojik Kanser veya Meme Kanserli Kadınların COVID-19 Pandemisi Sırasında Sağlık Bakımı Arama Davranışı, Psikososyal Belirtileri ve Sıkıntı Düzeylerinin Belirlenmesi

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ABSTRACT

Objective: The study was conducted to determine the health-seeking behaviors, psychosocial symptoms and distress levels and related factors of women diagnosed with gynecological or breast cancer during the pandemic period.

Materials and Methods: This descriptive, cross-sectional study was completed with a total of 109 women who had ovary, endometrium, cervix, vagina, vulva, or breast cancer. The study was conducted between October and December 2020, and data were collected online using an information form, Distress Thermometer and The Brief Symptom Inventory.

Results: There was a decrease in the frequency of going to the hospital for diagnosis (54.8%), treatment (32.3%), and rehabilitation (58%) services during the COVID-19 pandemic process. Our study results indicated that 89% of women experienced distress, according to Distress Thermometer. The mean Brief Symptom Inventory scores were found to be statistically significantly higher in women who stated that they experienced distress, whose chemotherapy treatment was postponed, and who obtained more information from the Internet during this period.

Conclusions: This study highlighted the pandemic's impact on healthcare-seeking behaviors and distress experiences of women with gynecological or breast cancer. Our results indicate a restriction on receiving health services during this period in women. Also, our results showed that most women experienced distress.

Keywords: Breast cancer, COVID-19, gynecologic neoplasms, healthcare-seeking behavior, psychological distress

ÖZ

Amaç: Bu çalışmanın amacı pandemi sürecinde jinekolojik veya meme kanseri tanı kadınların sağlık arama davranışları, psikososyal semptom ile distress düzeyleri ve ilişkili faktörleri belirlemektir.

Materyal ve Metot: Bu tanımlayıcı, kesitsel çalışma yurtdışı, endometrium, serviks, vajina, vulva veya meme kanseri olan toplam 109 kadınla tamamlanmıştır. Çalışma Ekim-Aralık 2020 tarihleri arasında gerçekleştirildi ve veriler bilgi formu, Distres Termometresi ve Kısa Semptom Envanteri kullanılarak çevrimiçi olarak toplandı.

Bulgular: COVID-19 pandemi sürecinde hastaneye tanı (%54,8), tedavi (%32,3) ve rehabilitasyon (%58) hizmetleri için başvurma sıklığında azalma olmuştur. Çalışma sonuçlarımız, Distres Termometresi'ne göre kadınların %89'unun distress yaşadığını göstermektedir. Distres yaşadığını ifade eden, kemoterapi tedavisi ertelenen, internetten bu süre içinde daha fazla bilgi edinen kadınlarda Kısa Semptom Envanteri puan ortalamaları istatistiksel olarak anlamlı derecede yüksek bulunmuştur.

Sonuç: Bu çalışma, pandeminin jinekolojik veya meme kanseri tanı kadınların sağlık arama davranışları ve distress deneyimleri üzerindeki etkisini anlamaya yardımcı olmuştur. Sonuçlarımız bu dönemde kadınlarda sağlık hizmeti almada bir kısıtlama olduğunu göstermektedir. Ayrıca, sonucumuz çoğu kadının distress yaşadığını göstermektedir.

Anahtar Kelimeler: Meme kanseri, Covid-19, jinekolojik tümörler, sağlık arama davranışı, psikolojik sıkıntı

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INTRODUCTION

The COVID-19 pandemic, a global public health crisis, is continuing to cause significant mortality and morbidity rates.^{1,2} In this process, while governments take serious measures to prevent the spread of the virus, health systems are struggling with the ever-increasing burden of new cases.³ As a reflection of the situation, both the healthcare system and healthcare providers in Türkiye, like those in other countries, have allocated a considerable part of their capacity in the fight against the COVID-19 pandemic. For this reason, access to some healthcare services, such as cancer care, is either not possible or delayed. Routine surgical procedures worldwide have almost stopped, and screening programs and diagnostic services have also been hampered. This situation raises the ethical question of whether cancer procedures can be delayed or not.⁴

Patients with cancer are vulnerable because of the potential effects of the treatment as well as the weakening of the immune system by the disease. When the COVID-19 process is added, these patients have become even more vulnerable.⁴ Due to the uncertainty of the COVID-19 process, the disruption of treatment and care services, and the postponement of surgical operations, patients with cancer unavoidably experience anxiety. Besides, social isolation and the 'need to stay home' lead to loneliness in patients with cancer, which is associated with a higher risk of mortality.⁵ In this process, the onset of flexible working hours in the clinics performing oncological surgeries has raised concerns that the prognosis of women diagnosed with cancer might be affected badly and that the intraoperative complications might increase. Also, women are more hesitant about presenting to health services due to the risk of infection.⁶ However, it has been reported that delaying curative surgery in those who have been diagnosed with gynecological cancer may have adverse outcomes for patients and affect survival significantly.⁷ It has been reported that breast cancer screening reduces mortality rates and that the five-year survival rate of patients with breast cancer in developed countries is over 80%, depending on early diagnosis and treatment. It is stated that the disruptions that may occur in these processes will also affect the survival process of patients with breast cancer.^{8,9}

Healthcare-seeking behaviors and even clinical outcomes of women diagnosed with cancer may be affected in this process. This study aimed to determine the change in the healthcare-seeking behaviors and distress levels of women with gynecological cancer or breast cancer during the pandemic.

MATERIALS AND METHODS

Ethical Committee Approval: This study was approved by the Ministry of Health Scientific Research Platform (2020-08-04T12_08_39) and the Gazi University Ethical Committee (Date: 24.09.2020, decision no: 91610558-604.01.02). In line with the Helsinki Declaration, the women were informed about the study, and their informed consent was obtained.

Study Design: The study used a descriptive, cross-sectional design. The paper is reported following the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement.

Population and Sampling: The population of the study consisted of women diagnosed with gynecological cancer or breast cancer in Türkiye. The sample size was calculated using the known population sampling calculation formula ($n = Nt^2pq / d^2(N-1) + t^2pq$).¹⁰ In this context, the Türkiye Cancer Statistics data, which represents the related Turkish population, were used as a reference.¹¹ Considering the pandemic process, the sample size (n) was calculated as 96 at a 90% confidence interval. The study was completed with a total of 109 women.

The inclusion criteria were women who were at least literate, volunteered to participate in the study, and had ovary, endometrium, cervix, vagina, vulva, or breast cancer.

Study Setting: The study was conducted online on social media platforms. The snowball method was used to spread the survey link created online. The questionnaire link was first shared on the researchers' individual social media accounts. Women who met the research criteria were invited to the research, and they were asked to share the link. The weblink to the questionnaire was shared on the Facebook® and Instagram® accounts of some cancer-related associations (such as Cancer Warriors Foundation, Breast Uterus Over - Cancer Warriors Foundation) and groups (such as Fight against Cancer, Dance with Cancer, Cancer Patients and Solidarity Group) that agreed to collaborate. The study data were collected between October and December 2020.

Data Collection Tools: An online questionnaire contained 18 items that aimed to collect data about the socio-demographic characteristics (age, education level, i.e.) of the participants and their healthcare-seeking behaviors during the pandemic process^{4,6}. Besides, the Distress Thermometer and The Brief Symptom Inventory were included in the questionnaire to determine the women's distress levels.

The distress thermometer was developed by Roth, Kornblinth, Batel-Copel, et al. in 1998 to measure psychosocial distress in patients with cancer.¹² The distress scale is graded between 0 and 10 with the thermometer analogy. It is a visual analogue scale that individuals can apply themselves and consists of

only one question. There is a thermometer visual with numbers from 0 to 10 on the scale. Subjects express their distress through the numbers on this thermometer. 0 points indicate that the individual does not experience any distress at all, and 10 points indicate that the individual experiences distress at the upper limit. The validity and reliability study of the scale in our country was carried out by Özalp, Cankurtaran, Soygür, et al. in 2007, and its cutoff point was determined as 4.¹³ Cronbach's alpha value of the scale in our study was found as .76.

The Brief Symptom Inventory (BSI) was developed by Derogatis (1992).¹⁴ This is a Likert-type self-assessment scale that scans mental symptoms. The validity and reliability study of the scale in our country was carried out by Şahin and Durak in 1997.¹⁵ The score range is between 0 and 212. It can be administered to adolescent and adult individuals and groups. There is no time limit for responding to the scale. BSI is a scale that consists of 53 questions defined by individuals and intended to recognize and measure various psychological symptoms. The scale consists of nine sub-dimensions: somatization, obsession-compulsion, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. There is a scoring key for each subscale based on the item numbers of the

sub-dimensions. For each question, the individual marks one of the five options ranging from (0) "Not at all" to (4) "Extremely." Each item is given a score of 0-4 according to whether the individual has any psychological symptoms and the extent to which they are present. High total scores obtained from the scale indicate that symptoms are frequent.¹⁵ Cronbach's alpha value of the scale in our study was found to be .96.

Statistical Analysis: The data stored in the e-mail account were transferred to the database of the SPSS 23.0 software package and evaluated. Descriptive statistics, such as frequency (n) and percentage distributions (%), t-test, one-way ANOVA, and Chi-square analyses, were employed to analyze the data. Statistical significance was accepted as $p < 0.05$.

RESULTS

The women's mean age was 44.79 ± 8.85 . According to the findings, 74.3% of women had breast cancer, and 11% had cervical cancer. The mean duration of cancer diagnosis was 35.70 ± 38.19 months. When the sources women used to get information about cancer from the internet were examined, it was found that 26.1% got information from doctor's pages (Table 1).

Table 1. Distribution of women's socio-demographic characteristics and cancer-related characteristics (n=109).

| Characteristics | | n (%) |
|---|---|---------------------------------|
| Mean age (Mean±SD) | | 44.79±8.85 (Min:22; Max:66) |
| Level of education | Primary/Secondary education | 27 (24.8) |
| | High school | 28 (25.7) |
| | University and above | 54 (49.5) |
| Employment | No | 36 (33) |
| | Quitted working during the pandemic process | 34 (31.2) |
| | Yes | 23 (21.1) |
| The longest place of residence during COVID-19 | Retired | 16 (14.7) |
| | Metropolis | 54 (49.6) |
| | Province | 29 (26.6) |
| | County | 19 (17.4) |
| Type of cancer | Town/village | 7 (6.4) |
| | Breast cancer | 81 (74.3) |
| | Cervical cancer | 12 (11) |
| | Ovarian cancer | 11 (10.1) |
| Duration of cancer/month (Mean±SD) | Endometrial cancer | 5 (4.6) |
| | | 35.70±38.19 (Min:1; Max:224) |
| Membership of a cancer-related association | No | 89 (81.7) |
| | Yes | 20 (18.3) |
| Sources used to get information about cancer from the internet^a | Doctor pages | 62 (26.1) |
| | Social media (such as Instagram, Facebook) | 55 (23.2) |
| | YouTube channels | 38 (16) |
| | Hospital pages | 37 (15.6) |
| | Blogs-forums | 22 (9.3) |
| | Mobile apps | 18 (7.6) |
| | Nursing pages | 5 (2.2) |

SD: standard deviation; Max: maximum; Min: minimum; ^a: n was multiplied because more than one option was marked.

According to the findings, 56.9% of the women stated a change in the frequency of going to the hospital / presenting to healthcare services during the pandemic. Also, there was a decrease in the frequency of going to the hospital for diagnosis (54.8%), treatment (32.3%), and rehabilitation (58%) services during the pandemic process. On the other hand, the planned doctor appointment of 28.1% was postponed/cancelled, the screening test of 26.8% was

postponed, and the treatment of 25.6% was delayed. Of the participants, 46.8% experienced a restriction in presenting to the hospital related to their disease, and of the women who experienced restrictions, 32% experienced restrictions due to fear of COVID-19 transmission, 30.9% due to the inability to get an appointment, and 21.6% due to the conversion of the hospital into a pandemic hospital (Table 2).

Table 2. Examination of the change in women's healthcare-seeking behaviors during the COVID-19 pandemic.

| Characteristics | | n (%) |
|--|--|-----------|
| Change in the frequency of going to the hospital / presenting to health services | Yes | 62 (56.9) |
| | No | 47 (43.1) |
| Change in the frequency of going to the hospital for DIAGNOSIS (such as pap-smear, mammography) | Increased | 8 (12.9) |
| | Decreased | 34 (54.8) |
| | No change | 20 (32.3) |
| Change in the frequency of going to the hospital for TREATMENT (such as chemotherapy, radiotherapy) | Increased | 6 (9.7) |
| | Decreased | 20 (32.3) |
| | No change | 36 (58) |
| Change in the frequency of going to the hospital for REHABILITATION (physical therapy, nutrition, health education, i.e.) | Increased | 2 (3.2) |
| | Decreased | 36 (58) |
| | No change | 24 (38.8) |
| Change in diagnosis, treatment, and rehabilitation processes for the disease | Yes | 39 (35.8) |
| | No | 70 (64.2) |
| Changes^a | My scheduled doctor's appointment was postponed/cancelled. | 23 (28.1) |
| | My screening tests were delayed. | 22 (26.8) |
| | My treatment (surgery, chemotherapy, radiotherapy, physical therapy, hormone therapy) was delayed. | 21 (25.6) |
| | I could not get consultancy service on medication use, nutrition, sleep, sexuality, i.e. | 11 (13.4) |
| | I presented to a private hospital because of the process in public hospitals. | 5 (6.1) |
| Experiencing a restriction in presenting to the hospital related to the disease | Yes | 51 (46.8) |
| | No | 58 (53.2) |
| Reasons for restrictions | I did not apply due to the fear of getting coronavirus. | 31 (32) |
| | The polyclinic/clinic that I was going to present to did not accept patients / I could not make an appointment. | 30 (30.9) |
| | The hospital that I was going to present to became a pandemic hospital. | 21 (21.6) |
| | I could not present to the hospital due to financial difficulties during the pandemic process. | 8 (8.3) |
| | My wife, friends, and family did not allow me to present to the hospital because of the possibility of coronavirus transmission. | 7 (7.2) |

^a: n was multiplied because more than one option was marked.

Before the pandemic period, health personnel (45%) ranked first, among women's cancer-related information sources; during the pandemic process, the internet (41.3%) rated first place (Table 3).

89% of the women were found to experience distress during the pandemic process. The mean BSI total score of the women was 58.31±42.28 (Table 4).

In women who experienced distress during the pandemic process, the mean BSI score was significantly higher than women who did not experience any distress (t=-4.691; p=0.000087). The mean BSI score of women whose chemotherapy treatment was delayed

during the pandemic period was significantly higher than those whose treatment was not delayed (t=2.694; p=0.026). The mean BSI score of women who experienced restrictions in presenting to the hospital as it had become a pandemic hospital was significantly higher than those who did not experience such a restriction (t=2.440; p=0.018). The mean BSI score of women who obtained more information from the Internet during the pandemic process was significantly higher than the women who received less information (F=3.076; p=0.032) (Table 5).

Table 3. The distribution of the sources that women obtained the most information about cancer before and during the pandemic.^a

| Healthcare personnel | Before the pandemic | | | Healthcare personnel | During the pandemic | | |
|----------------------|---------------------|------------|---------------------------|----------------------|---------------------|------------|---------------------------|
| | The Internet | Television | Books, journals, articles | | The Internet | Television | Books, journals, articles |
| n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) |
| 49 (45) | 45 (41.3) | 39 (35.8) | 32 (29.4) | 43 (39.4) | 45 (41.3) | 38 (34.9) | 34 (31.2) |

^a: n was multiplied because more than one option was marked.

Table 4. Examination of women's experience of distress during the COVID-19 pandemic process and the mean BSI scale scores.

| Scales | n (%) |
|---------------------------------------|------------------|
| Distress Thermometer | |
| <4 (No distress) | 12 (11) |
| ≥4 (Presence of distress) | 97 (89) |
| Mean BSI scale score (Mean±SD) | 58.31±42.28 |
| | (Min:4; Max:194) |

SD: standard deviation; Max: maximum; Min: minimum.

Table 5. Mean BSI scores of women according to their characteristics relating to the pandemic.

| | | Mean ± SD | F/t | p |
|--|---------------------------|--------------|--------------|-----------------|
| Distress status | <4 (No distress) | 26.50±21.45 | t=-4.691 | 0.000087 |
| | ≥4 (Presence of distress) | 62.24±43.73 | | |
| Status of delays in chemotherapy | Yes | 104.62±53.20 | t=2.694 | 0.026 |
| | No | 51.74±31.23 | | |
| Experiencing restrictions in presenting to the hospital because it has become a pandemic hospital | Yes | 72.47±44.44 | t=2.440 | 0.018 |
| | No | 46.26±32.33 | | |
| Status of obtaining information from the Internet | More ¹ | 68.17±45.21 | F=3.076 | 0.032 |
| | Much ² | 56.26±39.85 | | |
| | A little ³ | 34.40±35.27 | | |
| | Very little ⁴ | 63.16±43.86 | | |
| | | | Post-hoc 1-3 | |

F: One-way ANOVA; t: T-test in independent groups.

DISCUSSION AND CONCLUSION

Some guidelines suggest that non-emergency treatments be delayed during the COVID-19 process, while the World Health Organization recommends maintaining primary healthcare services, including the field of oncology.¹⁶

The frequency of going to the hospital for diagnosis, treatment and rehabilitation services was found to decrease during the pandemic in our study. More than a quarter of the women stated that their planned doctor appointment was postponed/cancelled, and their screening tests were postponed. Also, about a quarter of them said their treatment was delayed. In studies conducted with gynecologist and oncologists from various countries, it has been stated that there is a change in diagnosis and follow-up processes and that these processes have generally been postponed.¹⁷⁻¹⁹ In the literature, it has been seen that during the pandemic, there have been cancellations and delays in women's diagnostic processes, surgeries, treatment processes, scheduled doctor appointments, laboratory tests, and imaging applications.^{5,6,19} Although our study results appear to be similar to those of the literature, different results have also been observed in the studies conducted. In a study conducted with women with gynecological cancer, 64% of the participants stated that their treatment continued as planned despite the pandemic.²⁰ In another study examining breast cancer surgery experiences, it was stated that surgical operations were performed by taking precautions, and postoperative follow-up was carried out by using telemedicine methods. As a result of the study, it was stated that the patients were not infected with COVID-19.²¹ The reason for the different results in the literature may be because the studies were conducted in different countries.

The reasons for restrictions in presenting to health services in our study included the fear of COVID-19 transmission, not being able to get an appointment, and the conversion of the hospital that the participants would present to into a pandemic hospital. In a study conducted in the literature, participants stated that their breast examination was delayed because they were afraid of coronavirus transmission (81.9%) and could not get an appointment due to pandemic restrictions (12.1%).²² In another study, 53.1% of the participants stated that they were afraid of getting infected with coronavirus during hospital treatment and follow-ups, and 73.2% of them thought that patients with cancer were at risk for COVID-19 infection and that they were susceptible to COVID-19.²⁰ Our study is similar to the literature in terms of the reasons for the restriction in presenting to health services during the pandemic process. While women received information primarily from health personnel before the pandemic, they started receiving information mainly from the Internet dur-

ing the pandemic process. It was determined in a study that patients had difficulties in reaching the healthcare team during the pandemic.²³ As a result of our study, the reason for the change in women's information sources in favor of the Internet can be similarly considered to stem from the inability to reach healthcare personnel due to the changing health service delivery during the pandemic process. It is thought that the adoption of telemedicine applications as hospital procedures and their widespread use will both meet the information needs of patients and facilitate safe access to services.

The pandemic affects psychological symptoms such as stress, anxiety, and depression.²⁴ In our study, it was determined that 89% of women experienced distress. The mean BSI scores were found to be statistically significantly higher in women who stated that they experienced distress, whose chemotherapy treatment was postponed, who obtained more information from the Internet during this period, and who stated that they had limitations in presenting to the hospital during the pandemic process. Accordingly, it was found that these women experienced mental symptoms more frequently. In the literature, it was reported that 88.6% of the women were concerned, 51.4% experienced anxiety, and 26.5% experienced depression.⁵ In another study, it was stated that 35.3% of the women with gynecological cancer had a high level of anxiety and that 30.6% had a high level of depression score during the pandemic. The inability to get services from health institutions and the postponement of the treatment plans increases the patients' anxiety level. In the same research, 71% of the participants stated that they feared that the disease would progress if their treatment or follow-up were cancelled/delayed.²⁰ Similarly, the women in our study stated that there were restrictions in getting health services. Although our study findings seem to be similar to those of the literature, a different result was reported in another study. In the study investigating the effect of delaying breast examinations on breast and emotional symptoms, it was reported that there was no change in emotional symptoms, such as depression, feeling under pressure, or insomnia during the COVID-19 process.²² This may be because studies were conducted in different countries and with different patient groups. Considering that the pandemic process will not disappear in a short time, postponing the treatment and rehabilitation processes and not presenting to the hospital due to the fear of getting infected with COVID-19 are important issues because they will lead to the progression of cancer and cause patients to experience anxiety. Women who stated that they obtained more information from the Internet were found to experience more mental symptoms. This might be because they could not access correct information sources.

For this reason, considering the changes brought by the pandemic process, it is crucial to plan the health service delivery in a way that will not increase the anxiety and stress levels of patients.

In conclusion, our study found that during the COVID-19 pandemic process, women diagnosed with gynecological cancer or breast cancer experienced restrictions in accessing health services. There was a change in diagnosis-examination-treatment applications, existing conditions increased mental symptoms in women, and most women experienced distress. It is recommended that healthcare organizations should put alternative methods such as telehealth applications into practice so that susceptible and vulnerable patients with cancer can have uninterrupted access to treatment, healthcare, and counselling. It is also recommended that women diagnosed with breast or gynecological cancer be supported psychosocially during this process. The results obtained in the research are limited only to the women who participated in the study. Research data were obtained based on the participants' notifications and were not observed by the researchers. The strengths of our research are the use of valid and reliable measurement tools in the study and the fact that the data provides data regarding the period when the pandemic process peaked.

Ethics Committee Approval: This study was approved by the Ministry of Health Scientific Research Platform (2020-08-04T12_08_39) and the Gazi University Ethical Committee (Date: 24.09.2020, decision no: 91610558-604.01.02). In line with the Helsinki Declaration, the women were informed about the study, and their informed consent was obtained.

Conflict of Interest: No conflict of interest was declared by the authors.

Author Contributions: Concept – SÖŞ, SÇÖ, ŞYS, AŞE; Supervision – ŞYS, AŞE; Materials – SÖŞ, SÇÖ; Data Collection and/or Processing – SÖŞ, SÇÖ; Analysis and/ or Interpretation – SÖŞ, SÇÖ, ŞYS, AŞE; Writing – SÖŞ, SÇÖ.

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