



Concerns and expectations of patients with cancer in the COVID-19 pandemic: A prospective cohort study

Arif Hakan Önder^{1*}, Derya Kıvrak Salim¹, Mustafa Karaca¹, Selami Bayram¹, Armağan Aydın¹, Sevil Göktaş¹, Murat Koçer¹, Deniz Özbay Gediz¹, Mustafa Yıldız¹, Banu Öztürk¹

¹Antalya Training and Research Hospital Medical Oncology Clinic, Antalya, Turkey

²Psychiatry Clinic, Antalya, Antalya Training and Research Hospital, Turkey

*Corresponding author

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ABSTRACT

Introduction and Aim: Cancer affects people psychologically and organically. The emotional state of cancer patients is fragile and can be affected by many factors. We aimed to evaluate the effect of the COVID-19 pandemic on the mood and behavioral changes of cancer patients with solid cancer who are in follow-up and treatment.

Material and Method: A face-to-face questionnaire was filled in solid cancer patients without known psychological disorders who applied to the Medical Oncology outpatient clinic between 1-30 September 2021. The Hospital Anxiety and Depression Scale (HADS) and the scale examining the perspectives on COVID-19 were applied to the patients whose consent was obtained.

Results: A total of 235 people, participated in the survey. In the review of 202 completed surveys, 139 women and 63 men and the median age was 55 (23-83 years). In the study in which seventeen different solid cancer patients were evaluated, breast (52.5%), colon (19.3%) and lung (10.8%) cancers were most common. Most of the people who were more afraid of COVID-19 compared to cancer were patients who were on active cancer treatment. In the multivariate regression analysis, being on active treatment was found to be the only risk factor for 'being more afraid of COVID-19' compared to cancer. During COVID-19 pandemic, it was observed that 18 (8.9%) patients delayed their treatment/follow-up due to fear of COVID-19 infection. A high HADS anxiety score was observed in 58 (28.7%) patients, and a high HADS depression score was observed in 39 patients (19.3%).

Conclusion: Cancer patients are seriously worried about the progression of their cancer due to changes in follow-up or treatment due to COVID-19 pandemic. However, despite the associated risks, they were found to want to continue their treatment as planned.

Keywords: Anxiety, cancer, COVID-19, depression, ENGAGE, fear

Covid-19 pandemisinde kanser hastalarının endişeleri ve beklentileri: Prospektif bir kohort çalışması

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Öz

Amaç: Kanser insanları psikolojik ve organik olarak etkiler. Kanser hastalarının duygusal durumu kırılgandır ve birçok faktörden etkilenebilir. Takip ve tedavi gören solid kanserli kanser hastalarında COVID-19 pandemisinin ruh hali ve davranış değişiklikleri üzerindeki etkisini değerlendirmeyi amaçladık.

Bulgular: 1-30 Eylül 2021 tarihleri arasında Tıbbi Onkoloji polikliniğine başvuran, bilinen psikolojik rahatsızlığı olmayan solid kanser hastalarına yüz yüze anket formu dolduruldu. Onam alınan hastalara COVID-19 başvurusu yapıldı. Ankete 139 kadın ve 63 erkek olmak üzere toplam 235 kişi katılmıştır. Tamamlanan 202 anketin incelemesinde, ortalama yaş 55'tir (23-83 yaş). On yedi farklı solid kanser hastasının değerlendirildiği çalışmada en sık meme (%52,5), kolon (%19,3) ve akciğer (%10,8) kanserleri görüldü. COVID-19 'dan kansere kıyasla daha çok korkanların çoğu aktif kanser tedavisi gören hastalardı. Çok değişkenli regresyon analizinde, aktif tedavi görmek 'kanserden daha fazla korkmak' için tek risk faktörü olarak bulundu. COVID-19 pandemisi sürecinde 18 (%8,9) hastanın COVID-19 enfeksiyonu korkusuyla tedavi/takiplerini ertelediği görüldü. 58 (%28,7) hastada yüksek HAD anksiyete puanı, 39 hastada (%19,3) yüksek HAD depresyon puanı gözlemlendi.

Sonuç: Sonuç olarak; kanser hastaları, COVID-19 pandemisi nedeniyle takip veya tedavilerindeki değişiklikler nedeniyle kanserlerinin ilerlemesinden ciddi şekilde endişe duymaktadır. Ancak, ilişkili risklere rağmen, tedavilerine planlandığı gibi devam etmek istedikleri görüldü.

Anahtar sözcükler: Anksiyete, kanser, Covid-19, depresyon, ENGAGE, korku

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dr_hakanonder@hotmail.com

https://orcid.org/0000-0002-0121-5228

drmkaraca07@gmail.com

https://orcid.org/0000-0002-3954-5273

drarmaganaydin@gmail.com

https://orcid.org/0000-0001-8749-9825

muratkoocer71@hotmail.com

https://orcid.org/0000-0002-1541-640X

drmyildiz@yahoo.com

https://orcid.org/0000-0001-7832-5989

deryakivrak@gmail.com

https://orcid.org/0000-0003-4107-3460

drselamibayram@gmail.com

https://orcid.org/0000-0002-0930-5025

drsevilaktas@gmail.com

https://orcid.org/0000-0003-0976-5547

ozbayd2003@yahoo.com

https://orcid.org/0000-0002-8441-7705

drbanutr@yahoo.com

https://orcid.org/0000-0003-0290-8787

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Introduction

The COVID-19 pandemic has affected the whole world, especially advanced age, people with chronic diseases and cancer patients have been adversely affected by this process [1].

COVID-19 shows a different and severe course from any other known seasonal infectious disease or typical infections observed in immunosuppressed patients. It has been reported that COVID-19 infection is more mortal in cancer patients [2]. During the pandemic period, health systems all over the world were significantly challenged due to the rapidly increasing patient load. In order to prevent this highly contagious infection, regulations were made in health policies [3]. In the early part of the pandemic, large multidisciplinary associations published consistent recommendations for minimizing exposure to the virus [4,5,6,7]. Daily television news, social isolation, new mutations in the virus have triggered problems such as anxiety and depression in people.

In this presented study, it was aimed to examine the shocking effect of the pandemic and the effects of the regulations made in health care services on the mood and behavioral changes of cancer patients.

Method

On 2021, September 1-30, when the pandemic experienced its most devastating state in the world, a survey study was conducted for patients diagnosed with solid cancer who started Medical Oncology outpatient clinic. A written consent form was received from those who were accepted to participate, then a face-to-face questionnaire was filled out. The study protocol was approved by the Ethics Committee of Antalya Training and Research Hospital. The study was conducted in accordance with the Helsinki Declaration and data usage permission was obtained.

Inclusion criterias: 1) Being over 18 years old, 2) Being under follow-up and/or treatment for solid cancer, 3) Not having a known history of psychological disorders.

Exlusion criterias: 1) To have a psychiatric disorder such as bipolar disorder or schizophrenia that requires drug treatment 2) To use alcohol and psychotropic drugs 3) To have diseases such as dementia, mental retardation, 4) To refuse to participate in the survey.

In our survey, there was a Hospital Anxiety and Depression Scale (HADS) and a scale in which the patients' perspective on COVID-19 was evaluated (8). HADS is a scale designed to assess anxiety and depression that has been validated and proven to be effective in Turkey. It is a four-point likert-style scale consisting of 14 questions (range 0-3). On the HADS scale, which received a maximum of 21 points, those who scored ≥ 11 were considered psychological morbidity (abnormal); those who scored between 8-10 were classified as "borderline" and 0-7 as "normal". Anxiety and depression scores were calculated in accordance with the HADS questionnaire questions.

The scale, in which the perspective on COVID-19 is evaluated, was developed by Hacettepe University Faculty of Medicine Gültekin M. et al. and used in the Pan-European multicenter study (ENGAGE) during COVID-19 period (8). This questionnaire, consisting of 14 multi-choice questions to determine the perspectives of cancer patients during COVID-19 pandemic period, was included in our survey study after the necessary permissions were obtained. The answers to the questions about the effect of COVID-19 on patients were evaluated together with the HADS score.

Statistics: SPSS 25.0 (IBM Corp.) statistical package program was used in the analysis of the data. Surveys containing two or more missing or invalid questions were excluded from the study. Descriptive statistics of evaluation results; numbers and percentages for categorical variables, mean, standard deviation, median, and interquartile range (IQR) for numerical variables. Parameters that were significant in the univariate regression analysis were included in the multivariate regression analysis. Determined dependent variables were grouped categorically (0 and 1). All of the Likert type questions were divided into two; According to the aims of the research, strongly disagree, disagree and neither agree nor disagree were coded as '0'; I agree and strongly agree was coded as 1. Statistical alpha significance level was accepted as $p < 0.05$.

Results and Discussion

The questionnaire forms of a total of 235 patients were evaluated. 33 questionnaires were not included in the study due to lack of data. Of the patients, 139 were female and 63 were male. The median age was 55 years (range, 23-83). Of the patients, 179 (88.6%) were between the ages of 31-69, and 20 (10%) were ≥ 70 years old. The patients surveyed were found to have 17 different types of cancer. The three most common cancer types were breast (52.5%), colon (19.3%) and lung cancer (10.8%), respectively. Of the patients, 92 (45.5%) had at least one comorbidity. While 25 of them (12.4%) had two comorbid diseases; 19 (9.4%) had three or more comorbid diseases (Table 1).

132 (65.3%) of the patients were receiving active treatment. Of the patients who received active treatment, 73 (55.3%) were more afraid of COVID-19, mainly due to the suppression of their immune system caused by chemotherapy. Of the 70 patients who were followed up, 39 (55.7%) were more afraid of recurrence of cancer diseases. It was found that 78.8% of patients consider cancer disease as a risk factor for COVID-19. 51.5% of the patients found it more frightening to get COVID-19 than the progression of cancer, while 48.5% found the progression of their cancer more frightening. 83.2% (168) of the patients were concerned that their cancer would progress as a result of postponing or canceling their treatment or follow-up. 78.7% (159) of the patients had a

fear of being infected with COVID-19 from the hospital or clinic during their oncological treatment or follow-up

In our study, 51.5% of the patients were afraid of COVID-19 infection and 48.5% were afraid of cancer

disease. Although 78.7% of patients were aware of the risks associated with COVID-19, 83.2% feared that the cancer disease would progress if cancer treatment was interrupted during the pandemic.

Table 1. Demographics and HADS scores of patients

Patient (n=202)		
Age, year		54.9±11.2
Age group n (%)	Age ≤30	3 (1.5)
	31≤ Age ≤69	179 (88.6)
	Age ≥70	20 (9.9)
Live location n (%)	city	127 (62.9)
	county	70 (34.7)
	village/town	5 (2.5)
Gender n (%)	Female	139 (68.8)
	Male	63 (31.2)
Cancer Type n (%)	Breast cancer	106 (52.5)
	Gis cancer	44 (21.8)
	Gus cancer	24 (11.9)
	Lung cancer	22 (10.9)
	Others	6 (3.0)
Oncologic Situtation n (%)	Treatment	132 (65.3)
	Follow	70 (34.7)
Comorbidity n (%)	Yes	92 (45.5)
	No	110 (54.5)
HAS scale mean score (%25-75 IQR)	Anxiety	8.0 (4-13)
	Depression	6.0 (4-10)

When the settlements where the patients lived were grouped as provinces, districts and villages / towns, it was found that the average scores of anxiety and depression differed. While the average anxiety HADS score was the highest in the provincial center; the lowest were those living in the village/town (8 points vs. 5 points). The average depression HADS score, on the contrary, was highest in those living in the village/town, while it was lower in those living in the city center (7 points vs. 6 points).

When cancer types were compared with anxiety and depression scores, no statistically significant relationship could be found. However, the mean scores of anxiety were found to be higher in the group with breast cancer and gynecological cancers (8.3 and 8.2, respectively).

When the effect of the COVID-19 pandemic on patient care is examined; While it was observed that 88.1% (178) patients continued their care as planned despite the pandemic, it was found that only 18 (8.9%) patients did not go to treatment/follow-up appointments due to fear of COVID-19 infection. It was observed that 6 (3%) patients canceled their appointments in line with their own request or joint decision with their physician.

In multivariate regression analysis, active treatment (OR: 1.98; 95% CI: 1.03-3.80, p=0.03) and follow-up and treatment status disrupted in pandemic (OR: 3.42; 95% CI: 1.27-9.17, p=0.01) were identified as the risk factors for 'more fear of COVID-19 than cancer'. Being 65 years or

older, having comorbid diseases, female gender, living place, being a breast cancer patient, additional comorbidities, fear of not going in oncology due to pandemic; It was found that there was no significant effect on 'more fear of COVID-19 than cancer'. (Table 2).

It was observed that 111 patients (55%) did not know whether other patients affected by COVID-19 were being treated at the hospital/clinic where they were treated. Only 33.2% (67) of the patients had had a COVID-19 test before or during their treatment.

Follow-up and treatments of 34 (16.8%) patients were changed due to COVID-19. Respectively, 8 patients (4%) had delayed chemotherapy, 4 (2%) had chemotherapy doses reduced, 3 (1.5%) had their imaging canceled, two (1%) could not reach their doctor, two (1%) had delayed radiotherapy appointments, and 16 of them (7.9%) postponed their follow-up.

170 patients (84.2%) stated that their oncological follow-up or treatment was not delayed. It was determined that the treatment of 32 patients (15.8%) was delayed for a median of 7.21 (1-46) weeks.

'What is the most difficult problem you have during this period?' the question was answered by 180 patients. 119 patients (58.9%) reported pandemic-related problems, while 49 (24.3%) reported problems related to their cancer. Only 12 patients (5.9%) described the financial aspects caused by the pandemic as a challenging problem.

Table 2. Risk factors for more 'being more afraid of COVID compared to cancer': multivariate analysis (logistic regression)

Variable	Odds ratio	95% Confidence interval		p value
		Lower	Upper	
Age (<65 years)	1.14	0.54	2.37	0.72
Gender (female)	1.02	0.42	2.45	0.95
Breast cancer (yes)	1.25	0.53	2.91	0.60
Live location (city)	1.14	0.54	2.37	0.72
Oncological situation(Treatment)	1.98	1.03	3.80	0.03
Additional comorbidities (yes)	1.07	0.59	1.94	0.81
Fear of Not Going in Oncology Due to Pandemic (yes)	1.27	0.70	2.29	0.43
Follow-up and Treatment Status Disrupted in Pandemic (yes)	3.42	1.27	9.17	0.01

Table 3. Risk factors for abnormal (> 11) HADS anxiety score: multivariate analysis (logistic regression).

Variable	Odds ratio	95% Confidence interval		p value
		Lower	Upper	
Age (≥65 years)	1.48	0.52	4.18	0.45
Gender (male)	1.08	0.28	4.23	0.46
Breast cancer (yes)	1.76	0.48	6.46	0.45
Live location (city)	1.15	0.49	2.69	0.74
Oncological situation(Treatment)	1.40	0.56	3.52	0.46
Additional comorbidities (yes)	1.69	0.69	4.13	0.24
Fear of Getting COVID Infection in the Hospital (yes)	2.79	0.82	9.46	0.09
Fear of Not Going to Oncology Due to Pandemic (no)	5.58	1.91	16.3	0.002
COVID-19 fear more than cancer fear (yes)	1.98	0.79	4.99	0.14
Experience modification of care due to the pandemic (of any type) (yes)	1.19	0.40	3.51	0.74
HADS depression score (increased)	1.63	1.39	1.90	<0.001

The median values of HADS anxiety and depression scores were calculated as 8 (4-11) and 6 (4-10) points, respectively. HADS Anxiety score; It was calculated as normal in 95 (47%) patients, borderline in 49 (24.3%) and abnormal (high) in 58 (28.7%) patients. HADS Depression score was calculated as normal in 125 (61.9%) patients, borderline in 38 (18.8%) and abnormal (high) in 39 (19.3%) patients, respectively.

In multivariate logistic regression analysis, patients with abnormal HADS-anxiety scores were only fear of not going in oncology due to pandemic (OR: 3.48; 95% CI: 1.24-9.81, p=0.018) and increased HADS-depression score (OR: 1.63; 95% CI: 1.40-1.90, p<0.001) were found to be

significantly related. Apart from these, age, gender, being in follow-up or treatment, having breast cancer, comorbidity status, being afraid of COVID-19 more than cancer, fear of to get COVID infection in the hospital, fear of not going to oncology due to pandemic and to experience modification of care due to the pandemic (of any type). None of these had an effect on anxiety. (Table 3)

In the multivariate logistic regression analysis performed on patients with abnormal HADS-depression scores (ie ≥11), only increased HADS-anxiety scores were associated with higher depression scores (OR: 1.77; 95% CI: 1.45-2.15, p<0.001). Apart from these, age, gender,

being in follow-up or treatment, having breast cancer, comorbidity status, being afraid of COVID-19 more than cancer, fear of to get COVID infection in the hospital, fear of not going to oncology due to pandemic and to

experience modification of care due to the pandemic (of any type). None of these had an effect on depression. (Table 4)

Table 4. Risk factors for abnormal (i.e. 11–21) HADS depression score: multivariate analysis (logistic regression)

Variable	Odds ratio	95% Confidence interval		p value
		Lower	Upper	
Age (<65 years)	1.48	0.46	4.71	0.50
Gender (female)	1.77	0.47	6.55	0.39
Breast cancer (no)	1.45	0.43	4.89	0.54
Live location (village/town)	1.34	0.53	3.37	0.53
Oncological situation(Follow-up)	1.55	0.58	4.11	0.37
Additional comorbidities (no)	1.80	0.73	4.48	0.20
Fear of Getting COVID Infection in the Hospital (no)	1.01	0.29	3.53	0.97
Fear of Not Going to Oncology Due to Pandemic (yes)	1.73	0.61	4.90	0.29
COVID-19 fear more than cancer fear (yes)	2.11	0.84	5.26	0.10
Experience modification of care due to the pandemic (of any type) (yes)	1.39	0.47	4.12	0.55
HADS anxiety score (≥ 11)	17.54	7.00	43.97	<0.001

Our trial; It is a survey study that examines the opinions, fears and perspectives of solid cancer patients in our center about the changes due to the COVID-19 pandemic in all solid cancer patients.

As it is known, cancer is one of the major risk factors for the development of COVID-19. In a study examining the data of 1524 cancer patients who applied to the Cancer Treatment Center of Wuhan University, it was reported that the risk of contracting COVID-19 was twice as high in cancer patients compared to the general population (16, source). However, in our study, it was found that most patients feared COVID-19 more than cancer (51.5% vs. 48.5%). Although most patients (78.7%) were aware of the risks associated with COVID-19, their main concern was the development of progressive disease (83.2%) if cancer treatment was interrupted during the pandemic.

As expected, there was a strong correlation between depression and anxiety in our study ($p < 0.001$). As the depression scores of the patients increased, it was observed that they paid less attention to fears such as fear of the progression of the disease and not being able to go to the oncology doctor because of the pandemic, but this relationship could not be shown with the anxiety score

groups. There is evidence to suggest that psychological stress may affect the onset or progression of cancer (10). Therefore, it is important for clinicians to consider the psychological stress status of patients. However, in our study, it was found that 'more fear of COVID-19 than cancer' did not affect anxiety and depression levels.

In the ENGAGE pan-European gynecology study conducted in 2020 (8), HADS-anxiety score averages were found to be lower than the anxiety score in our study in 2021. In our study, the average HADS-depression score was found to be lower. This result may be due to the gradual increase in the level of anxiety due to the developing large peaks, and an important reason for this increase in anxiety in our patients is the concern that their disease may progress as a result of the gradual disruption of cancer treatment or follow-up.

It has been shown that different geographical features may cause different perceptions of the pandemic (8,11). In our study, which was carried out in a single center, anxiety and depression scores were different in smaller settlements with different sociocultural characteristics, but statistical significance could not be reached due to patient limitation. In our study, anxiety was higher in

those living in the city center and depression was higher in village/town residents.

An increase in anxiety and depression due to COVID-19 was reported in a study in patients with breast cancer (12). In our study, the mean scores of anxiety were high in the group with breast cancer and gynecological cancers, but statistical significance could not be obtained.

In our study, during the pandemic period, in the hospital where the patients were treated and followed; it was determined that the information about the COVID-19 situation, the infected health personnel and the vaccine was quite insufficient. This situation was thought to be an indication of the failure to provide transparent information to patients about the pandemic.

Our limitations in the study; 1) Patients who did not come to the clinic in any way due to much more serious anxiety at the time of the study and patients who needed home care could not be reached, so this group could not be included in the study. 2) Patients were randomly selected for the survey, so no equivalence could be achieved between the groups in terms of the number of patients in cancer types. 3) The number of patients is limited.

Our study shows that we as clinicians should consider not only physical health but also psychological health when trying to cure diseases. Because, as defined by the World Health Organization, "Health is not merely the absence of disease or infirmity, but a state of complete physical, mental and social well-being". In times of serious threats such as pandemics, a holistic approach is required in order for patients to cope with both known cancer conditions and anxiety and depression caused by the pandemic.

Conclusion

In this presented study, it was shown that patients with solid tumors of different histological types and followed up in the Medical Oncology clinic have increased anxiety about the progression of their cancer due to changes in their follow-up or treatment in the COVID-19 pandemic. The study is important in terms of showing how patients perceive the changes related to diagnosis, treatment or follow-up during extraordinary crisis periods such as pandemics.

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