

# The COVID-19 pandemic and patients with endometriosis: A survey-based study conducted in Turkey

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## Abstract

**Objective:** To apply rapid online surveying to determine the knowledge and perceptions of the COVID-19 pandemic on patients with endometriosis in Turkey.

**Methods:** An online survey was conducted by the Turkish Endometriosis & Adenomyosis Society and administered to patients with endometriosis who agreed to participate in the study. The survey included 25 questions prepared by an expert committee of four professionals (two gynecologists and two endometriosis specialists).

**Results:** Of the 290 questionnaires sent out, 261 (90%) were returned. A total of 213 (83.86%) patients reported that they were afraid of having endometriosis-related problems during the pandemic period. In addition, 133 (53.63%) patients thought the management of their endometriosis was affected because of the pandemic.

**Conclusion:** Clinical studies clearly indicate that endometriosis is a condition associated with high levels of chronic stress. The COVID-19 pandemic has led the public to experience psychological problems such as post-traumatic stress disorder, psychological distress, depression, and anxiety. The majority of patients with endometriosis were afraid of having endometriosis-related problems during the pandemic period. The majority of elective endometriosis surgeries have not been postponed. Patients were highly aware of the pandemic and practiced social distancing and hygiene. Only 4 (1.59%) patients with endometriosis required hospitalization.

## KEYWORDS

COVID-19; OB/GYN; Pandemic; Physician; Stress; Survey

## 1 | INTRODUCTION

The novel coronavirus disease 2019 (COVID-19) has become a source of significant stress and worry for everyone, especially since WHO categorized the outbreak as a pandemic. The uncertainty about the effects of the virus on individuals, lack of a cure, and lack of a vaccine are the main reasons for this stress.<sup>1</sup> The Centers for Disease Control and Prevention has included certain patients with chronic heart and lung conditions and patients with auto-immune disorders using immune suppressants in the high-risk group.<sup>2</sup> However, due to the novelty of the virus, there is a lack of data concerning risk stratification. Patients

with a variety of chronic diseases are wondering whether they belong to the high-risk group.<sup>3</sup>

Endometriosis is a chronic condition affecting 5%–10% of women of reproductive age. There are approximately 190 million women worldwide with this disease.<sup>4</sup> Due to the complexity and ambiguity of the symptoms, a delay in diagnosis is common and may be as long as 10.4 years.<sup>5</sup> In addition, its etiology is not completely understood.<sup>6,7</sup> The delay in diagnosis and the severity of pain-related symptoms cause considerable physical, psychological, and social burden on the patients' lives.<sup>8</sup> These negative impacts of the disease can lead to a reduction in health-related quality of life.

Theoretically, patients with endometriosis are not considered among the COVID-19 high-risk group, because even though it is a chronic inflammatory condition, it does not always manifest itself in the thoracic region and immune suppressants are not a part of its medical management. However, patients with pulmonary/thoracic endometriosis, especially those with a history of collapsed lung, lung resection, or cardiothoracic surgery, likely belong to the high-risk group.<sup>9</sup> Furthermore, patients with intestinal and/or renal manifestations of endometriosis and in whom an extensive disease could be detected by the presence of ileus or hydronephrosis can also be included in the high-risk group.<sup>9</sup>

Previous studies have shown that survivors of acute infectious diseases, such as SARS, can experience anxiety, depression, stress, and post-traumatic stress disorder.<sup>10-12</sup> However, due to the novelty of COVID-19 and the fact that people are experiencing a pandemic for the first time in their lives, there are no data regarding its long-term physical and psychological effects. Furthermore, the association of COVID-19 with other diseases is still unclear. It is well-acknowledged that stress and anxiety can exacerbate symptoms of endometriosis, especially those associated with pain.<sup>13,14</sup> Therefore, understanding the stress and anxiety related to the COVID-19 pandemic and their effects on the symptoms of endometriosis is important in the management of the disease during and after the pandemic period.

The aim of the present study was to evaluate the levels of anxiety and stress caused by the pandemic among patients with endometriosis in Turkey.

## 2 | MATERIALS AND METHODS

The present prospective survey study was conducted in Turkey between April 5 and April 20, 2020. A total of 290 patients with endometriosis whose contact information was on the Turkish Endometriosis & Adenomyosis Society's database received the survey link by email and via social media ([www.endometriosis.org](http://www.endometriosis.org)). A total of 261 patients who completed the survey were included in the study. Informed consent was considered given upon completion of the survey. The principles of the Declaration of Helsinki were followed in carrying out the present study. The study was approved by the local Ethics Committee (2020/155) and National Research Committee, and was registered on ClinicalTrials.gov (NCT04337346).

A self-administered online survey consisting of 25 questions was developed using SurveyMonkey® (SurveyMonkey, San Mateo, CA, USA; <http://www.surveymonkey.com>). An weblink to the online survey was sent out to all patients who had a history of endometriosis of more than 1 year. The youngest participant was 22 years old and the oldest was 50 years old. Patients who had a previous diagnosis of a psychiatric disease and were under medical treatment, who experienced a major trauma or a disease within the past year, or who were pregnant were excluded from the study.

The survey included a total of 25 questions about the demographic characteristics of respondents and questions about their basic

knowledge of COVID-19. The questions were prepared by an expert committee of four professionals (two gynecologists and two endometriosis specialists). Furthermore, questions evaluating fear and stress caused by the pandemic and assessing patients' attitudes towards COVID-19-related precautions were also included.

The data from the completed surveys were saved on the SurveyMonkey® database and analyzed using Stata Version 14 for Windows (StataCorp LLC, College Station, TX, USA). Continuous data were checked for normality of distribution using the Shapiro-Wilk test. Continuous data that did not fit a normal distribution were described as median (interquartile range). Categorical data were described as frequency (percentage).

## 3 | RESULTS

A total of 261 (90%) patients with endometriosis completed the survey. The Cronbach alpha coefficient of the questionnaire was 0.78 with an acceptable internal consistency. The mean age of patients and the mean time passed since the diagnosis of endometriosis were  $34.19 \pm 5.90$  years and  $7.02 \pm 5.67$  years, respectively. Of the participants, 68.90% were married, 73.81% received a clinical diagnosis of endometriosis, 26.19% had a surgical confirmation, 57.71% were operated due to endometriosis, 37.35% are still under medical treatment, 50.40% reported use of analgesics, 36.40% used a single medication, and 14% used multiple medications.

Data reflecting concerns about endometriosis during the pandemic period are shown in Table 1. A total of 213 (83.86%) patients reported that they were afraid of having endometriosis-related problems during the pandemic period. In addition, 133 (53.63%) patients thought that the management of their endometriosis was affected because of the pandemic. Similarly, 21 (8.57%) patients had their endometriosis surgeries postponed due to the cancellation of all elective surgeries during the pandemic (Table 1).

Data on patients' knowledge of COVID-19 and their attitudes towards the pandemic precautions are presented in Table 2. Most of the participants stated that they have been following the rules and maintaining a healthier lifestyle: 248 (98.02%) patients documented that they have been practicing social distancing and 253 (99.61%) patients stated that they have been paying more attention to their hand hygiene than they did before the pandemic.

## 4 | DISCUSSION

According to the survey, the majority of the patients with endometriosis did not consider themselves among the high-risk group for COVID-19. However, they were still scared of experiencing endometriosis-related problems during the pandemic. More than half of the participants reported that they had problems regarding the management of their disease. The majority of the participants were highly aware of the pandemic-related precautions and they practiced self-hygiene and social distancing. With alterations to their lifestyles,

**TABLE 1** Stress related to the COVID-19 pandemic and its effects.<sup>a</sup>

Has your pain increased during the pandemic period?	Yes	111 (44.22)
	No	140 (55.78)
Have you stopped taking your medications during the pandemic period?	Yes	20 (8.97)
	No	203 (91.03)
Do you think you are in the high-risk group?	Yes	104 (41.11)
	No	149 (58.89)
Are you afraid of experiencing endometriosis-related problems during the pandemic?	Yes	213 (83.86)
	No	41 (16.14)
Has the management of your endometriosis been affected by the pandemic?	Yes	133 (53.63)
	No	115 (46.37)
Have you started taking any additional medications?	Yes	52 (20.72)
	No	199 (79.28)
What do you do at home in order to relax?	Yoga	30 (12.15)
	Breathing exercises	21 (8.50)
	Meditation	18 (7.29)
	Sleep	58 (23.48)
	Watch TV, Netflix	120 (48.58)
Has your planned endometriosis surgery been postponed because of the pandemic?	Yes	21 (8.57)
	No	224 (91.43)
Are you afraid that your gynecologist might become unavailable during the pandemic period?	Yes	158 (62.95)
	No	93 (37.05)

<sup>a</sup>Values are given as number (percentage).

the participants managed to cope with their disease during the pandemic period.

It has been reported that patients with endometriosis experience high levels of stress due to the negative impact of the endometriosis-related symptoms on all aspects of life, including work, relationships, and fertility.<sup>15</sup> According to Graham et al.,<sup>16</sup> patients with endometriosis reported higher levels of stress and higher depression scores, especially those with endometriosis stages 3 and 4.<sup>16</sup> In the present study, although results were not compared with that of a control group, it was also shown that patients with endometriosis are afraid of experiencing endometriosis-related problems during the pandemic period.

Pelvic pain is the most common symptom of endometriosis. It is known that under stress, pain-related symptoms could be exacerbated.<sup>17</sup> Painkillers such as non-steroidal anti-inflammatory drugs do not alter the course of COVID-19 despite an earlier report that stated that use of ibuprofen worsened the outcomes.<sup>18</sup> In addition, an increased risk with the usage of acetaminophen group medications has not been reported. In the present study, an increase in the intake of medications such as paracetamol (acetaminophen) has been observed. The majority of patients were still able to control their symptoms of pain with analgesics. However, multiple drug regimens

**TABLE 2** Questions specific to the COVID-19 pandemic.<sup>a</sup>

Do you practice social distancing?	Yes: 248 (98.02)
	No: 5 (1.98)
Have you started paying more attention to your hand hygiene?	Yes: 253 (99.61)
	No: 1 (0.39)
Have you experienced a COVID-19-related symptom (fever, dry cough, shortness of breath, fatigue, loss of smell and taste)?	Yes: 28 (11.07)
	Required hospitalization: 4 (1.59)
	No treatment was necessary: 24 (98.41)
	No: 225 (88.93)
Have you started eating healthier?	Yes: 178 (70.63)
	No: 74 (29.37)
Did you have a healthy diet before the pandemic?	Yes: 189 (74.70)
	No: 64 (25.30)
How is your sexual life affected during the pandemic period?	Positive: 9 (4.09)
	Not affected: 132 (60.00)
	Negative: 79 (35.91)

<sup>a</sup>Values are given as number (percentage).

were lower than expected. Additionally, an increase in the consumption of dietary supplements could be deducted from the study, which is a trend that has been observed worldwide since the outbreak of the COVID-19 pandemic.

Sleep is also another parameter that is easily affected by stress and/or anxiety. It has already been reported that patients with endometriosis experience poor quality of sleep due to endometriosis-related pain.<sup>19,20</sup> Stress and anxiety caused by the pandemic itself might affect sleep status of individuals negatively.<sup>3</sup> In the present study, it is seen that a small number of patients started having sleeping problems; however, the majority of the patients expressed that they find sleeping relaxing.

The sexual life of patients with endometriosis is negatively affected, especially for patients with stage 3 and 4 endometriosis. Dyspareunia is the most common symptom reported by these patients.<sup>21</sup> According to the survey results, 35% of patients with endometriosis reported that the pandemic had a negative impact on their sexual lives. This negative impact was most probably due to fear of contagion via close contact. A total of 60% of patients reported no change regarding their sexual lives.

The benefits of a regular yoga practice, breathing exercises, and meditation have already been suggested in the treatment of endometriosis.<sup>22</sup> It is proposed that these activities lower levels of systemic cortisol by activating the parasympathetic nervous system, which in return lowers stress levels and alleviates pain-related symptoms.<sup>23</sup> Respondents of the survey also reported practicing yoga, breathing exercises, and meditation in order to deal with pandemic-related stress and stated positive outcomes. These activities could be categorized as self-treatment modalities.

At the time of writing, on July 7, 2020, there are 3682673 people who have been tested for COVID-19 in Turkey and 206844 (0.5%) are confirmed positive.<sup>24</sup> Out of the confirmed cases, there have been 5241 (0.2%) fatalities. Of the patients who participated in the survey, 28 (11.07%) had tested positive for COVID-19, and out of these 28

patients, 4 (1.59%) had been hospitalized. All patients recovered fully. A certain percentage of patients with endometriosis have become infected during the pandemic in Turkey as well as worldwide. However, due to the lack of data, this percentage is unclear and a consensus on the management of endometriosis during the pandemic is still inconclusive.

The present study has some limitations, such as the lack of a control group, the lack of insight into the patients' state of minds and levels of stress before the outbreak, and the lack of objectivity in the anxiety scoring. However, the high number of participants and lack of data regarding endometriosis and the COVID-19 pandemic makes the present study unique. Prospective long-term studies with control groups are needed to see the long-term effects of the COVID-19 pandemic.

In conclusion, the pandemic has been a stress-laden period among patients with endometriosis as it has been for all humanity. The majority of patients with endometriosis are afraid of having endometriosis-related problems during the pandemic period. An increase in the usage of analgesics has been reported. The majority of the elective endometriosis surgeries have not been postponed. Patients are highly aware of the pandemic and practice social distancing and hygiene. Only 4 (1.59%) patients with endometriosis required hospitalization. It can be seen that patients are able to deal with the pandemic with appropriate recommendations and changes in lifestyles. In fact, patients with endometriosis have adapted healthier lifestyles.

#### AUTHOR CONTRIBUTIONS

PYB contributed to the conception and design. CK contributed to the statistical analysis and revision of the manuscript. NFTS contributed to the drafting and critical revision of the manuscript. IP contributed to the interpretation of data. ATU was responsible for the acquisition of data. EO was responsible for drafting the manuscript and supervision.

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#### CONFLICTS OF INTEREST

The authors have no conflicts of interest.

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