PEDIATRIC ALLERGY, IMMUNOLOGY, AND PULMONOLOGY
Volume 00, Number 00, 2022
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DOI: 10.1089/ped.2021.0081

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Psychological State of Parents of Children with Primary Immunodeficiencies During the COVID-19 Pandemic

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Background: COVID-19 has affected humanity not only physically but also mentally. It was expected to have impact on high-risk groups such as the immunocompromised patients and parents/caregivers of them. Our study was aimed to investigate the COVID-19related anxiety, post-traumatic stress levels, and sleep-related parameters of the parents of children with primary immunodeficiency.
Methods: Parents of children with primary immunodeficiency and age and gender-matched control group completed questionnaires.
Results: Anxiety and post-traumatic stress levels of the study group were found to be significantly higher than the control group. Furthermore, sleep time of the study group was significantly lower than the control group. The subjective sleep quality of the study group was also lower in the study group, but the difference did not reach a significant level.
Conclusions: In the ongoing and other possible pandemic processes, professional support for the parents of these children is of great importance.

Keywords: anxiety, COVID-19, pandemic, post-traumatic stress disorder, primary immunodeficiency

Introduction

A NUMBER OF PANDEMICS have occurred in the past, in which millions of people have lost their lives or have experienced lifelong effects from the diseases. The latest of these pandemics emerged in Wuhan, China, at the end of 2019. It was determined that the agent was a novel coronavirus (officially named as severe acute respiratory syndrome coronavirus 2 or SARS-CoV-2) that has not been isolated from humans, and the World Health Organization (WHO) has recognized the disease as COVID-19 (COrona VIrus Disease-2019).[1,2]

COVID-19 has varying effects on individuals worldwide.[3] More than 1 million people have died, with many more becoming ill; this number continues to increase day by day. Increased mortality and morbidity are associated with risk factors such as advanced age and comorbid conditions related to immunocompromisation.[4] Over the course of the pandemic, many challenges have emerged in the daily life of ordinary people, such as social restrictions, closure of schools and workplaces, and most importantly the increased risk of losing their lives and loved ones. As a result, unemployment, economic hardships, and psychosocial problems such as feelings of loneliness, depression, and anxiety have increased in the general population.[5,6]

Primary immunodeficiencies (PIDs), also known as inborn errors of immunity, arise from defects in genes that especially affect the immune system and are present with increased susceptibility to infections with a wide range of severity (simple to life threatening). Inborn errors of

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immunity were traditionally considered to be rare diseases, affecting ~1 in 10,000–50,000 births. However, with the ongoing discovery of novel inborn errors of immunity and the concerted definition of clinical phenotypes, the collective prevalence is more likely to be at least 1/1,000–1/5,000.[7–9] Previous studies have consistently shown that children with PIDs and their parents are at significant risk in terms of physical health as well as social well-being and functioning.[10,11]

Frequent infections, regular hospital check-ups, hospitalization if deemed necessary, and the necessity of certain treatments such as monthly intravenous immunoglobulin (IVIg) therapy in hospitals can negatively affect the daily life and education of children with PIDs. For these reasons, caregivers of children with PIDs also experience elevated psychological distress.[12]

COVID-19 has been a turning point for parents of children with PIDs as well as for humanity. Even in the absence of a pandemic, children with PIDs face a number of risks due to defects in their immune system, which require caregivers to be constantly alert to potential risks. Furthermore, considering that immunocompromised patients have a high risk for infectious diseases including viral infections such as COVID-19, deciding between going to the hospital to continue treatment and ''shielding'' (isolation at home) has become a challenge for families during the pandemic.[13,14] In this context, the current COVID-19 pandemic has emerged as a public health issue that exacerbates the preexisting psychological distress of parents of children with PIDs.

Post-traumatic stress disorder (PTSD) among parents of children with severe physical illnesses is a public mental health concern.[15] PTSD is associated with substantial morbidity, reduced quality of life, high levels of medical utilization, and high economic costs in addition to being a heavy burden on child care.[16,17] The recent outbreak of the COVID-19 pandemic will inevitably lead to a surge of post-traumatic stress symptoms in different groups of people in the future, and some evidence for this has already emerged.[18]

Children with PIDs are one of the riskiest groups in terms of both physical and mental health during the pandemic; however, to the best of our knowledge, there is no study on the psychological status of immunocompromised children or their parents in this period. This study aimed to evaluate the anxiety and post-traumatic stress symptoms of the parents of children with PIDs during the COVID-19 pandemic.

Materials and Methods

Participants

A total of 34 parents of children with PIDs who were followed up between June and September 2020 in the pediatric allergy and immunology outpatient clinic at Akdeniz University Hospital (Antalya, Turkey) were selected. Two parents were not included in the study because they were illiterate, and 1 parent did not want to fill out the forms; thus, the final study group consisted of 31 parents recruited from 65 patients with PIDs who were followed up in this outpatient clinic.

The parents of patients who were admitted to the intensive care unit or pediatric service at that time were not included as this may affect the results. No participant had been infected with COVID-19 at the time of the study. As the control group, the parents of healthy children were matched with those in the study group in terms of gender and age. The participants in the control group were recruited from the relatives of hospital staff.

Informed consent

All participants were informed of the study, and their written consent was obtained. Approval was obtained from the ethics committee of Akdeniz University Faculty of Medicine (no: 70904504/502).

Measures

Sociodemographic data form. This form was used to evaluate the sociodemographic characteristics of children and parents, disease-related parameters (duration, age of diagnosis, treatment, etc.), and social media usage habits of parents during the pandemic.

COVID-19 knowledge form. This form was created by researchers for this study and was used to assess the parents' knowledge about COVID-19 (Table 1).

Generalized anxiety disorder 7-item. Generalized anxiety disorder 7-item (GAD-7) was developed by Spitzer and others to evaluate generalized anxiety disorder according to *Diagnostic and Statistical Manual of Mental Disorders-IV*-TR criteria.[19] It is a 7-item 4-point Likert-type (0: none, 1: many days, 2: more than half of the days, 3: almost every day) self-report scale that evaluates the experiences asked in the scale items in the last 2 weeks. Scores of 5, 10, and 15 are the cutoff points for mild, moderate, and severe anxiety, respectively. The reliability and validity of the GAD-7 scale have been confirmed for the Turkish population by Konkan et al.[20]

Post-traumatic stress disorder checklist civilian version. The scale is a validated 17-item self-report scale assessing the severity of traumatic stress symptoms.[21] The 3 symptom domains include re-experiencing (5 items), avoidance (7 items), and hyperarousal (5 items). Subjects were asked to choose the most appropriate response according to how much they have been affected in the last month after a stressful event. Each question provides a 5-point Likert-type assessment and is scored between 0 and 4. The total score of the scale is the sum of the responses given to the items. In a study of the scale for the Turkish population, the cutoff score of the scale was specified as between 22 and 24, and both specificity and sensitivity were found to be >70% at this cutoff point. The Turkish adaptation of the scale was performed by Kocabaşoğlu et al.[22]

Table 1. COVID-19 Knowledge Form

1.	In which country was COVID-19 first seen?
2.	Which country has the highest number of cases so far?
3.	In which month most cases have been reported so far in Turkey?
4.	What are the most common symptoms of COVID-19?
5.	How is COVID-19 treated?
6.	Who are considered as the riskiest groups?
7.	What are the most effective protection methods?
8.	How many days is the recommended quarantine period in case of doubt?
9.	How long is the recommended physical distance?
10.	How is COVID-19 transmitted?

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Sleep-related parameters. Two questions of the Pittsburgh Sleep Quality Index were used to evaluate the sleep duration and subjective sleep quality of the participants.[23,24]

Statistical analysis

The numerical variables in the study are presented as the mean and standard deviation, frequency, or percentage. The compatibility of the numerical variables to normal distribution was evaluated using the Shapiro–Wilk test. Student's *t*-test was used for normally distributed variables, and the Mann–Whitney *U* test was used for variables that were not normally distributed. The relationship between categorical variables was examined using the χ^2 test. Spearman's correlation analysis was performed to evaluate the relationship between the anxiety scale score, PTSD scale score, and COVID-19 knowledge survey score. The study was conducted with a 95% confidence level, and *P*-values <0.05 were considered statistically significant.

Results

The baseline characteristics of the study group are summarized in Table 2. The demographic data of the participants in this study are presented in Table 3. Of the 31 parents in the study group, 22 (71%) parents were mothers and 9 (29%) parents were fathers. There was no significant difference between the study and control groups in terms of age and gender. In addition, there was no significant difference between the study and control groups in terms of height, weight, monthly income, number of siblings, number of people living at home, presence of an individual over the age of 65 years, and decreased income during the COVID-19 pandemic. The rate of consanguineous marriage between parents was 25.8% in the study group and 6.5% in the control group.

The social media usage habits of the participants during the pandemic were examined; although there was no significant difference between the 2 groups, both active social media use and the time spent on social media during the COVID-19 pandemic were higher in the control group.

A comparison of the anxiety levels of the study and control groups revealed that anxiety levels were significantly higher in the study group than in the control group ($P < 0.01$). In the study group, 10 (32.2%) participants had mild anxiety, 5 (16.2%) participants had moderate anxiety, and 16 (51.5%) participants had severe anxiety. In contrast, there were 21 (67.7%), 7 (22.5%), and 3 (9.6%) participants with mild, moderate, and severe anxiety, respectively, in the control group. When the PTSD levels of the groups were compared, post-traumatic stress disorder checklist civilian version (PCL-C) scores were significantly higher in the study group than in the control group ($P < 0.01$).

Participants were asked about their sleep duration during the COVID-19 pandemic, and their responses were grouped as ''less than 6 hours'' and ''more than 6 hours.'' A comparison of the sleep-related parameters of the groups revealed that the proportion of parents with a shorter sleep duration (<6 h) was significantly higher in the study group than in the control group ($P < 0.05$). Similarly, the subjective sleep quality of the participants was grouped as ''good'' and ''poor.'' Although the subjective sleep quality of parents in the patient group was worse than that of parents in the control group, there was no statistically significant difference between the 2 groups ($P = 0.07$).

There was no significant difference between the 2 groups in terms of the total number of correct answers given to the questions in the COVID-19 knowledge questionnaire. In addition, there was no significant correlation between the total number of correct answers and GAD-7 and PCL-C scores. In the study group, no significant relationship was found between active social media use and correct answers to the questions in the COVID-19 knowledge survey. In addition, no significant relationship was found between the time spent on social media and answering the questions correctly. Table 4 gives the comparison of the groups in terms of scale scores, sleep-related parameters, and questionnaire results.

Table 2. The Baseline Characteristics of the Patient Group

Age of diagnosis (months)	34.45 ± 44.25
Age of onset (months)	17.8 ± 31.43
Duration of follow-up	51.87 ± 49.36
Diagnoses of patients with PID	
X-linked agammaglobulinemia	11 (35.5%)
Common variable ımmunodeficiency	9 (29%)
Severe combined immunodeficiency	4 (12.9%)
Hyper IgM syndrome	1 (3.2%)
DiGeorge sydrome	1 (3.2%)
Ataxia telangiectasia	1 (3.2%)
STAT3 mutation	1 (3.2%)
CASP8 mutation	1 (3.2%)
CD55 deficiency	1 (3.2%)
IRF8 mutation	1 (3.2%)
Primary pediatric vaccination	
Completed	17 (54.8%)
Incomplete	14 (45.2%)
Comorbidities	
Yes	11 (35.5%)
No	20 (64.5%)
Psychiatric comorbidities	
Yes	5 (16.1%)
No	26 (83.9%)
Treatment	
Antibiotic prophylaxis	12 (38.7%)
Antifungal prophylaxis	4 (12.9%)
IVIg	27 (87.1%)
Immunosupressive	5 (16.1%)
Others	10 (32.3%)
History of hospitalization	
Yes	17 (54.8%)
No	14 (45.2%)
History of ICU hospitalization	
Yes	3 (9.7%)
No	28 (80.3%)
History of BMT	
Yes	3 (9.7%)
No	28 (80.3%)
Familial history of PID	
Yes	3 (9.7%)
No	28 (80.3%)

BMT, bone marrow transplantation; ICU, admission to an intensive care unit; IVIg, intravenous immunoglobulin; PID, primary immunodeficiency.

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Table 3. The Demographic Data of the Subjects

	Patient group (n: *31*)	*Control group* (n: *31*)	P
Age (months)[a]	86.06 ± 62.37	86.83 ± 61.78	0.89
Gender (male)[b]	20 (64.5%)	20 (64.5%)	0.99
Maternal age (years)[a]	34.52 ± 5.49	34.42 ± 5.58	0.82
Paternal age (years)[a]	39.48 ± 8.52	38.94 ± 6.00	0.93
Maternal education[b]			
Primary school or illiterate	12 (38.7%)	11 (35.5%)	
Secondary or high school	12 (38.7%)	8 (25.8%)	0.34
University or above	7 (22.6%)	12 (38.7%)	
Paternal education[b]			
Primary school or illiterate	7 (22.6%)	3 (9.7%)	
Secondary or high school	15 (48.4%)	18 (58.1%)	0.38
University or above	9 (29%)	10 (32.3%)	
Presence of any maternal disease[b]			
Yes/no	7/24	6/25	0.76
Presence of any paternal disease[b]			
Yes/no	3/28	5/26	0.71
Number of siblings[a]	1.19 ± 0.7	1.16 ± 0.87	0.74
Monthly income (tl)[a]	4,129.03	4,464.52	0.16
Age above 65 years old (yes/no)[b]	7/24	4/27	0.32
Number of occupants in the household[a]	4.3 ± 0.74	4.1 ± 0.87	0.42
Place of living[b]			
Urban	17 (54.8%)	30 (96.8%)	**0.01**
Rural	14 (45.2%)	1 (3.2%)	
Type of delivery[b]			
Vaginal	11 (35.5%)	21 (67.7%)	**0.01**
C/S	20 (64.5%)	10 (32.3%)	
Consanguineous marriage (yes/no)[b]	8/23	2/29	**0.04**
Near presence of individual with COVID-19 (yes/no)[b]	5/26	13/18	**0.03**
Decrease in income during pandemic (yes/no)[b]	14/17	14/17	>0.99
Active social media use (yes/no)[b]	20/11	26/5	0.08
Time spent on social media[b]			
<1 h per day	23 (74.2%)	17 (54.8%)	0.11
≥1 h per day	8 (25.8%)	14 (45.2%)	
Source of information[b]			
TV	24 (77.4%)	22 (71%)	0.56
Official social media accounts	11 (35.5%)	11 (35.5%)	0.99
Nonofficial social media accounts	2 (6.5%)	3 (9.7%)	0.64

Significant p values were shown as bold.
[a]Mann–Whitney U test.
[b]Chi-square test.

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The anxiety and post-traumatic stress scores of mothers ($n = 22$) and fathers ($n = 9$) were compared in the study group, and no significant difference was found. Among parents in the patient group, higher GAD-7 and PCL-C scores were associated with a significantly shorter sleep duration (Table 5). According to Spearman's correlation analysis, there was a statistically significant positive correlation between the GAD-7 and PCL-C scale scores of parents in the patient group (r: 0.710, $P < 0.001$) (Table 6).

Discussion

In this study, anxiety levels were significantly higher in the study group than in the control group. In the study group, 51.5%, 16.2%, and 32.2% of parents had severe anxiety, moderate anxiety, and mild anxiety, respectively. Post-traumatic stress scores were also higher in the study group than in the control group.

Chronic diseases in childhood may affect the psychosocial well-being of children and their families. In general, parents are responsible for the care of a child with a chronic disease, which requires them to balance the child's health care needs with those of other family members and work commitments. However, parents may have difficulty in accepting the child's diagnosis and prognosis and suffer from anxiety about the child's future welfare.[25] Taking care of children with chronic and potentially life-threatening diseases may be stressful for families.[26] Consequently, parental anxiety symptoms have been found to be associated with lower quality of life and lower scores in adaptive behavior domains. Furthermore, parental anxiety may increase the anxiety of their children.[27]

There are some studies on the psychological issues of patients with PIDs; however, studies evaluating the psychological aspects of the parents of patients with PIDs are limited. In a previous study, health-related quality of life was considerably poorer among patients with PIDs than among those in the healthy control group.[28]

Table 4. The Comparison of the Groups in Terms of Scale Scores, Sleep-Related Parameters, and Knowledge Form Results

	Patient group (n: 31)	*Control group (n: 31)*	P
GAD-7[a]	9.32 ± 6.06	4.19 ± 4.07	**0.001**
Severity of anxiety[b]			**0.001**
Mild	10 (32.3%)	21 (67.7%)	
Moderate	5 (16.1%)	7 (22.6%)	
Severe	16 (51.6%)	3 (9.7%)	
PTSD-civilian version[a]	27.65 ± 16.63	12.32 ± 10.77	**<0.001**
Sleep time[b]			
<6 h	16 (51.6%)	7 (22.6%)	**0.018**
≥6 h	15 (48.4%)	24 (77.4%)	
Subjective sleep quality[b]			
Good	9 (29%)	16 (51.6%)	0.07
Poor	22 (71%)	15 (48.4%)	
Number of correct answers of COVID-19 knowledge form[a]	8.06 ± 1.46	7.68 ± 1.70	0.48

Significant p values were shown as bold.
[a]Mann–Whitney U test.
[b]χ^2 test.
GAD-7, generalized anxiety disorder-7; PTSD, post-traumatic stress disorder.

It is unclear whether the cause of the deterioration in self-esteem, physical functioning, and family activities is the type of illness (including specific diagnosis and duration or age at diagnosis), treatment factor (eg, frequency of IVIg treatment), or patient's chronic health condition. Nevertheless, the family's perceived burden of the disease seems to be a key factor.[28] In a study conducted by Kuburevic et al., compared with healthy peers and children with juvenile idiopathic arthritis, children with PIDs had significantly lower total scores in both parent-reported and children-reported Pediatric Quality of Life Inventory.

It was reported that 6 (24%) of 25 children had significant anxiety symptoms, and 5 (20%) children had significant depressive symptoms.[10] In another study that assessed the psychiatric impact on the parents of 26 PID patients, the most significant stressors for parents were the presence of anxiety for an extended duration, the lack of a definitive treatment for the disease, and the side effects and complications in treating the child.[29]

Table 5. Correlation Between Scale Scores and Sleep Time

	Sleep time		
	<6 h	*≥6 h*	P
PTSD-civilian version[a]	34.13 ± 13.24	20.73 ± 17.48	**0.011**
GAD-7[a]	11.94 ± 4.97	6.53 ± 5.97	**0.022**

Significant p values were shown as bold.
*Mann–Whitney U test.
GAD-7, generalized anxiety disorder-7; PTSD, post-traumatic stress disorder.

Table 6. Correlation Between Generalized Anxiety Disorder 7-Item and Post-Traumatic Stress Disorder Checklist Civilian Version Scores

r	*GAD-7*	*PTSD-civilian version*	*Number of correct answers of COVID-19 knowledge questionnaire*
GAD-7	—	**0.710**[a]	–0.065
PTSD-civilian version	**0.710**[a]	—	–0.013
Number of correct answers of COVID-19 knowledge form	–0.065	–0.013	—

[a]Spearman correlation analysis.
GAD-7, generalized anxiety disorder-7; PTSD, post-traumatic stress disorder.

In our study, the anxiety and post-traumatic stress levels of the parents in the study group during the COVID-19 pandemic were higher than those of the parents in the control group. Parents in the patient group had higher anxiety and post-traumatic stress levels as they could be worried that their child may have frequent and severe infections due to immune system defects. Moreover, some of the treatments (IVIg) for children with PIDs are administered in the hospital; thus, they had to visit the hospital during the pandemic, which can cause anxiety.

However, the parents of healthy children in the control group may skew the results. Furthermore, the ratio of those living in rural areas to those living in urban areas was significantly higher in the study group than in the control group; this may also affect the results in this study.

Some studies have been conducted during the COVID-19 pandemic on children with chronic diseases and their caregivers. In a study on children with chronic lung diseases and their parents, they were found to have higher anxiety levels due to the COVID-19 pandemic, and the parents used more mature coping strategies to manage stress during the pandemic.[30] In another study conducted in June 2020, the mothers of children with cystic fibrosis, especially those aged 0 to 12 years with cystic fibrosis, had higher trait anxiety scores than the mothers of healthy children. In addition, most of the mothers of children with cystic fibrosis reported that their anxiety levels were decreased after the interview.[31]

In a study exploring the experiences, information, and support needs, and decision making of parents with a child with cancer during the COVID-19 pandemic, it was found that most of the parents were worried about SARS-CoV-2 and the possibility of transmitting the virus to their child if they were infected. During the first month of the lockdown in the United Kingdom, many parents reported that the hospital was no longer considered as a safe place.[14] However, in contrast, a study reported that the additional stress from COVID-19 did not impair the psychosocial functioning of children with cancer and their families.[32]

In our study, a 10-question knowledge form, which was created by researchers for this study to evaluate the knowledge levels of the participants about COVID-19, was used. No relationship was found between the total number of correct answers in the questionnaire and the anxiety and

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PTSD scale scores. In addition, no significant difference was found between anxiety and PTSD scale scores and between those with and without COVID-19–positive individuals in their close environment. The findings may be explained by the small sample size.

This study is the first to evaluate the mental health of parents of children with PIDs during the COVID-19 pandemic. However, there are some limitations in the study. First, the study was a cross-sectional study. The mental state of the parents before the COVID-19 pandemic was not evaluated. Therefore, it is unknown whether the differences between the study and control groups are attributed to the COVID-19 pandemic or the adverse effects on sleep and mental health when caring for children with chronic medical conditions.

In contrast, parents may experience less stress due to being able to spend more time at home with their children during the COVID-19 pandemic or because everyone is wearing masks in public areas during the COVID-19 pandemic, which could reduce the possibility of infections. Regarding sleep habits, parents caring for medically ill children will likely have more sleep disturbances than parents who have healthy children even in the absence of a pandemic. In contrast, the pandemic may have improved their sleep habits (working from home or children not attending school may allow more time for sleeping).

However, we cannot conclude on this without examining the data on the sleep quality of the parents before the pandemic. Second, other psychopathologies beyond anxiety and PTSD were not evaluated for the parents. Third, the control group consisted of healthy children. It would be more appropriate to add another control group consisting of children with other chronic diseases. Fourth, children with PIDs were not evaluated in this study because the majority of the patients were young, and some children were not suitable for psychiatric interviews and scale scoring due to their mental limitations. Fifth, PIDs are rare diseases, and the actual number of patients cannot be accurately determined due to the concerns of parents about visiting the hospital during the COVID-19 pandemic.

Conclusion

This study revealed that the anxiety and post-traumatic stress levels of parents of children with PIDs were higher than those of parents of healthy children. The COVID-19 pandemic presents a mental health challenge, and the after effects of the pandemic can be greatly different between the parents of patients affected by chronic diseases and the general population. The findings demonstrated the importance of professional psychological support for the parents of children with PIDs in the current and possible future pandemics.

Parents play an important role in helping their child adapt to living with chronic diseases. Therefore, psychological therapies for parents could improve their mental health and enhance the overall psychological well-being of the family.[33] Future studies are needed to evaluate the psychological status of these parents and the effects of psychological interventions during the COVID-19 pandemic.

Authors' Contributions

B.A. conceived of the presented idea. B.A. and A.Ö. developed the theory and performed the computations. D.F.K.U., E.Ç. chose and directed the appropriate patients for the study. A.Ö. and Ö.G.Ç. carried out literature review and verified the analytical methods. B.A, A.E, and Z.E.S. mainly wrote the article. A.S.A. and A.B. supervised the findings of this study. All authors discussed the results and contributed to the final article.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

No funding was received for this article.

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Received for publication May 4, 2021; accepted after revision December 27, 2021.

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