ORIGINAL ARTICLE: COVID 19

PEDIATRIC PULMONOLOGY WILEY

Depression and anxiety in mothers of home ventilated children before and during COVID-19 pandemic

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Abstract

Background: Due to advances in technology, home ventilation in children has increased in recent years. The provision of proper care for a home-ventilated (HV) child can have a strong impact on the lifestyle of caregivers. The aim of this study was to evaluate the depression and anxiety levels of the mothers of HV children during the current COVID-19 pandemic and compare them to those of mothers of healthy peers.

Methods: This cross-sectional study was conducted on HV children ($n = 21$) and a control group of healthy peers ($n = 32$) by means of a questionnaire completed by the mothers of the children of both groups. Psychometric scales, such as the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory-State (STAI-S), and the State-Trait Anxiety Inventory-Trait (STAI-T), were used to assess participants.

Results: During the pandemic signs of depression were present in 8 (38.1%) of the case group and 8 (25%) of the healthy control group. Comparison of the BDI scores from before and during the pandemic showed no difference between mothers of the HV children ($p = .09$). Scores for BDI and STAI-T were higher in the case group than in the control group, whereas there was no significant difference in STAI-S scores.

Conclusion: Depression and anxiety levels of mothers of HV children were found to be higher during the COVID-19 pandemic. Economic, medical, and social support resources are needed to reduce levels of depression and anxiety and help mothers of those children dependent on technology.

KEYWORDS
caregiver, mental health, pandemic

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1 | INTRODUCTION

Due to advances in technology and medicine, health services are having to find ways to deal with the increasing number of families that manage the home-care of technology-dependent children. Providing home care to those children has a significant impact on the lifestyle of caregivers. Caring for their children at home may lead to conflict between spouses, emotional overload or guilt because they feel they are neglecting their other children.[1] It is, therefore, important to ensure that appropriate health-care services and adequate funding for equipment and caregivers are available; the needs of ventilator-assisted children living at home are extremely variable and the risk of caregiver burnout is high.[2] Studies of both adult and pediatric populations have reported a high prevalence of caregiver depression amongst those managing patients on home mechanical ventilation, especially when support and resources are limited.[3–6] A reduction in the amount of total sleep time and possible problems at work may also contribute to caregivers' depression and anxiety.

Mental health has an impact on well-being and the ability to cope with daily challenges.[7] Theoretically, mental health directly influences the personal and social functioning of individuals with respect to quality of life and hence may also be associated with social and economic burdens of care.[8] These burdens may have a negative impact on mental and physical health and may lead to an increased risk of mortality.[9] In some studies, parents perceived a worse quality of life than the patients themselves did; recognition and enhancement of quality of life of the caregivers, therefore, is of paramount importance for their mental health.[1] In addition, in some studies, social support available to caregivers has been found to affect their level of depression. A study including caregivers of adult patients suggested that perceived social support may be more important than actual enacted support.[10]

In December 2019, a novel outbreak of a previously unknown disease began in China and spread rapidly throughout the world within a few months. The World Health Organization labeled this disease, caused by a new coronavirus, COVID-19.[11] On March 11, 2020, the first case of COVID-19 infection was confirmed in Turkey. Since COVID-19 infection in children seemed to have a milder disease course and a better prognosis than in adults, at the beginning of the pandemic it was thought that patients with underlying disease may have increased risk of morbidity and mortality.[12]

Previous studies of epidemics and pandemics have shown that anxiety and worries about health are widespread in these times.[13] In a recent study from China, more than half of the responders stated that they had concerns, in general, about the pandemic, or that family members could have COVID-19.[14] Posttraumatic stress disorder and mental health problems may occur in mothers of technology-dependent children after an acute disease that may affect the child's care.[15] In Turkey it is usually mothers who take on the role as the main caregiver of home-ventilated (HV) children. While just living with an HV child can cause depression and anxiety in mothers, struggling with a pandemic at the same time may considerably increase depression and anxiety levels, and this anxiety in mothers of HV children may lead to neglect in the care of their children. The early detection of mental health issues in such parents is crucial so that early targeted intervention can be implemented and the impact on parental home care minimized.

The sudden emergence of the COVID-19 epidemic caused concerns amongst both medical staff and patients and there were also disruptions in routine outpatient control visits of chronic patients due to the severe containment measures implemented by the government.[15] To our knowledge there is no study comparing depression and anxiety levels in the mothers of HV children with the mothers of healthy peers during COVID-19. The primary aim of this study was to investigate the prevalence of anxiety and depression in mothers of HV patients before and during the COVID-19 pandemic and compare it with the mothers of healthy children. The secondary aim was to investigate the factors related with depression and anxiety and the correlation between the study variables and scores of the Beck Depression Inventory (BDI), State-Trait Anxiety Inventory-State (STAI-S), and State-Trait Anxiety Inventory-Trait (STAI-T) scales.

2 | METHODS

2.1 | Patients and study design

This is a controlled, cross-sectional study that involved mothers of patients on home-ventilation that are followed by the Division of Paediatric Pulmonoloy in the Faculty of Medicine at the Marmara University in Istanbul. The mothers of 21 HV children from 33 patients previously evaluated for depression and anxiety 3 years ago, replied to the same questionnaires again during the pandemic. A control group of 32 mothers of children with no health problems during the pandemic also participated in the study.[16]

Mothers were invited to complete the BDI, the STAI-S, and the STAI-T surveys. Mothers of patients who had been decannulated ($n = 2$), died ($n = 2$), or could not be reached ($n = 8$) were excluded from the study. Completion of the questionnaires was done by telephone via a call by the same physician. The case group was defined as the mothers of HV children. The control group was selected from the peers of the HV patients. Mothers in the control group were similar in age, educational status, and sociodemographic characteristics. Mothers with a diagnosis of any comorbid disease or psychiatric disorders and/or having another child or family member who needs special health care were excluded from the study.

2.2 | Instruments

Turkish versions of BDI, STAI-S, and STAI-T were completed by the mothers. The BDI questionnaire was used to measure current, self-reported symptoms of depression. It includes 21 questions related to symptoms of depression, each question being scored from 0 to 3. Total scores yielded for each completed questionnaire ranged from 0

to 63. Higher scores imply the existence of higher levels of depression. The Turkish validity and reliability studies of this inventory were performed by Hisli.[17] A score of 11–17 is defined as mild depression; a score of 18–23, moderate depression, and a score of 24 or higher, severe depression.[18] The State-Trait Anxiety Inventory is a self-report questionnaire consisting of two subscales (state anxiety and trait anxiety), each including 20 items evaluating the level of anxiety. STAI-S describes the person's feelings at a specific moment and under particular conditions, whereas the STAI-T scale is used to describe how subjects generally feel. The responses to each item in the anxiety questionnaire are assigned a score from 1 to 4. Possible scores vary from 20 to 80, with higher scores indicating more anxiety.[19] The Turkish validation study of STAI was conducted by Oner and Le Compte.[20] In our study, scores ≥40 for STAI-S were accepted as the presence of state anxiety and the same scores of ≥40 for STAI-T were accepted as the presence of trait anxiety.[21]

2.3 | Ethical approval

The study protocol was designed in compliance with the Declaration of Helsinki. Informed consent was obtained from study participants and the study was approved by the Ethical Committee of the Medical Faculty of Marmara University.

2.4 | Statistical analysis

SPSS v.22 was used for statistical analysis. Continuous variables were expressed as mean ± SD for normally distributed data and median (25th, 75th percentile) for data that were not normally distributed. The Kolmogorov–Smirnov test was used to assess the normality of sample distribution. Nonparametric Mann–Whitney U and χ^2 tests were used for comparison between patients and controls. The Kruskal–Wallis test was used to compare the means. Spearman's correlation analysis was used to evaluate the relationship between various variables. The Wilcoxon test was used to compare related samples. The p value of less than .05 was considered significant.

3 | RESULTS

Mothers of HV (n = 21) and healthy (n = 32) children were included in the study.

The characteristics of the groups are presented in Table 1. The age and gender of the children, the age, educational level, marital status, and employment of the mothers, the number of siblings, household number and income were similar in the two groups. Thirteen of the mothers were managing the child themselves, without any support. The patients' characteristics are shown in Table 2.

TABLE 1 Characteristics of children and mothers of the study

Demographic data	Case group n = 21	Healthy group n = 32	p Value
Age of the children (months), mean ± SD	128.5 ± 63.9	103.5 ± 41.1	.28
Female sex, n (%)	12 (57.1)	18 (56.3)	.94
Number of siblings, median (25–75 per)	1 (0–2.5)	1 (1–2)	.67
Age of the mothers (years), mean ± SD	40.6 ± 7.4	38.4 ± 6.3	.58
Occupation, n (%)			
Employed	2 (9.5)	4 (12.5)	.55
Unemployed	19 (90.5)	28 (87.5)	
Education of mother, n (%)			
Uneducated	2 (9.5)	0 (0)	
Elementary/middle school	10 (47.6)	16 (50)	.34
High school	5 (23.8)	10 (31.3)	
University	4 (19)	6 (18.8)	
Marital status, n (%)			
Married	19 (90.4)	30 (93.7)	.52
Divorced	2 (9.5)	2 (6.2)	
Number of the people living at home, median (25–75 per)	4 (3–5)	4 (4–5)	.79
Total monthly household income, n (%)			
Under poverty threshold	19 (90.4)	32 (100)	.15
Over poverty threshold	2 (9.5)	0 (0)	

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TABLE 2 Characteristics of the HV patients

The age at the initiation of HV (months), median (25–75 per)	36.0 (11.5–89.0)
Months on home ventilation, median (25–75 per)	59.0 (47.5–80.0)
Diagnosis, n (%)	
Neuromuscular disease	10 (47.6)
Chronic lung disease	3 (14.3)
Congenital central hypoventilation	3 (14.3)
Cerebral palsy	3 (14.3)
Metabolic disease	1 (4.8)
Down syndrome	1 (4.8)
Duration of ventilation, n (%)	
<16 h/day	14 (66.7)
>16 h/day	7 (33.3)
Type of ventilation, n (%)	
Ventilation via tracheostomy	10 (47.6)
Noninvasive ventilation	11 (52.4)
Oropharyngeal suctioning, n (%)	11 (52.4)
Feeding, n (%)	
Oral	13 (61.9)
Nasogastric tube	2 (9.5)
Gastric tube	6 (28.6)
Mobility, n (%)	
Independent movement	7 (33.4)
On wheelchair	4 (19)
No independent movement	10 (47.6)
Schooling, n (%)	
No education	12 (57.1)
Home school	6 (28.6)
Full-time school	3 (14.3)

Abbreviation: HV, home-ventilated.

The BDI and STAI scores of parents are shown in Table 3. Depression was present in 8 (38.1%) of the case group and 8 (25%) of the healthy control group (HC). Four of the case group had mild, one of them had moderate and three of them had severe depression. From the HC group, six had mild depression, one had moderate depression and one had severe depression. Before the pandemic, depression was present in 12 (57.1%) of the case group. Five of these mothers had mild, three of them had moderate and four of them had severe depression.

Before the pandemic, the mean BDI score of the case group was 16.6 ± 10.5. Comparison of the BDI scores before and during the pandemic showed no difference ($p = .09$). The results of STAI-S and STAI-T were also similar ($p = .11$, $p = .46$, respectively). The comparison of the scores of depression and anxiety before and during the pandemic are presented in Table 3.

State anxiety was present in 9 (42.8%) mothers from the case group and 7 (21.8%) mothers from the healthy group; trait anxiety was present in 15 (71.4%) and 12 (37.5%), respectively. The comparison between the case and healthy groups showed that the case group had higher BDI and STAI-T scores than the healthy group, whereas there was no significant difference in STAI-S scores (see Table 3).

The relationship between the depression and anxiety scores of the mothers and the study variables was analyzed and is shown in Tables 4 and 5. The mothers who continued to work were found to have worse scores of BDI and STAI-T (BDI $p = .04$; STAI-T $p = .04$). It, therefore, suggests that giving up work had a positive effect on the depression and anxiety levels of the mothers. The BDI score of mothers who did not communicate with other families with an HV child was found to be higher than the communicating mothers ($p = .03$). Mothers of patients requiring suctioning had a significantly higher STAI-S score than those of patients not suctioned ($p = .04$). The number of people living at home had a significant correlation with the depression score in the case group ($p = .01$).

TABLE 3 Comparison of depression and anxiety levels

(a) Mothers of HV children before and during pandemic		
	Case group during pandemic (n = 21) mean ± SD	Case group before pandemic (n = 21) mean ± SD	p Value
BDI	11.5 ± 8.2	16.6 ± 10.5	.09
STAI-S	38.1 ± 10.2	43.6 ± 11.8	.11
STAI-T	44.8 ± 8.8	47 ± 9.1	.46
(b) Mothers of HV children and the mothers of healthy children during pandemic		
	Case group (n = 21) mean ± SD	Control group (n = 32) mean ± SD	p Value
BDI	11.5 ± 8.2	7.2 ± 1.3	**.03**
STAI-S	38.1 ± 10.2	35 ± 1.8	.23
STAI-T	44.7 ± 8.8	39.6 ± 1.1	**.04**

Note: Bold p values: $p < .05$.

Abbreviations: BDI, Beck Depression Inventory; HV, home-ventilated; STAI-S, State-Trait Anxiety Inventory-State; STAI-T, State-Trait Anxiety Inventory-Trait.

TABLE 4 The factors related with depression and anxiety in case group during pandemic

	BDI p value	STAI-S p value	STAI-T p value
Giving up the job	**.04**	.45	**.04**
Communication with other families with an HV child	**.03**	.05	.34
Caregiving help from others	.58	1.00	.17
Suctioning	**.04**	**.04**	.46
Type of feeding	.05	.42	.41
Type of ventilation	.05	.12	.16
Underlying disease	.59	.06	.10
Maternal education	.12	.77	.86
Gender	.21	.28	.22
Total income	.33	.28	.95

Note: Bold p values: p < .05.

Abbreviations: BDI, Beck Depression Inventory; HV, home-ventilated; STAI-S, State-Trait Anxiety Inventory-State; STAI-T, State-Trait Anxiety Inventory-Trait.

Seven of the mothers of HV children (33%) were supported by other family members for night care. Three grandmothers, two fathers, and two sisters were supporting the mothers. Average weekly care time by someone other than the mother was 39 h, however, none of the families had day or night time nursing support. Levels of anxiety and depression were not affected whether the mother received additional care support from others or not (p > .05). In the case group, the BDI score was positively correlated with the STAI-T score (r = .67; p = .001).

4 | DISCUSSION

During the COVID-19 pandemic, according to the BDI and STAI questionnaires, anxiety and depression levels in mothers of the HV patients were higher than in the controls. To our knowledge, this is the first study comparing depression and anxiety levels in the mothers of HV children and the mothers of healthy ones during the COVID-19 pandemic. Caring for a child who needs home ventilation may affect the psychological health of the primary caregiver.[6] Mothers often play a key role in the caring and decision-making processes and the burden of this role may, therefore, have a negative effect on well-being and produce symptoms of stress in mothers.

In developing countries, financial and human resources are lacking for HV patients. In our study group, the annual income of almost all families was below the poverty threshold according to national standards.[22] Even additional governmental financial support is not enough to cover the cost of a device that would increase the patient's comfort level or to employ a special care nurse. The cost of equipment required for home ventilation is totally reimbursed by the national health system, but there is a lack of experienced home care personnel, including nurses, physiotherapists, and psychologists. In a study by Carnevale et al.,[23] much of the distress reported by the caregivers of HV children was related to their encounters with health and social services. A lack of a broader range of support for the whole family and inadequate management of home care therapy may increase depression and anxiety levels in caregivers. Some other studies have described the lack of understanding for the needs of the family by decision-making authorities as being due to the complicated bureaucracy in health care systems.[24,25] The only reliable way to identify caregivers who require additional extra support is through discussion of their individual concerns.[26] Home care facilities and support for chronic disorders are not well established in Turkey, as is the casein many other developing countries.

In the current study, BDI scores of mothers who did not receive social group support were worse than mothers who received social support. Families seek additional support through patient associations or other families of children with similar conditions. Mah et al.[24] reported the importance of preventing the isolation of families of HV children to control the stress derived from the care of these patients. O'Brien et al.[27] highlighted the importance of maintaining contact with other families in similar conditions To share experiences, information on different treatments, care, and family functioning. Other authors have also pointed out the need to

TABLE 5 Correlation coefficient (r) between the study variables and scores of the BDI, STAI-S, and STAI-T

	Case group before pandemic			Case group during pandemic			Control group during pandemic		
	BDI	STAI-S	STAI-T	BDI	STAI-S	STAI-T	BDI	STAI-S	STAI-T
Child's age	−0.281	−0.364	0.058	0.400	−0.194	0.281	0.060	−0.077	0.137
Mother's age	−0.227	−0.269	−0.132	0.357	−0.357	0.100	−0.023	0.049	0.212
Number of siblings	0.274	−0.156	−0.211	0.380	−0.223	−0.008	0.097	**0.384**	0.076
Duration of ventilation support	−0.278	−0.178	−0.007	0.209	0.355	0.346	–	–	–
Number of the people living at home	0.147	−0.127	0.214	**0.594**	−0.113	0.372	0.026	**0.372**	0.132

Note: Bold r values: p < .05.

Abbreviations: BDI, Beck Depression Inventory; HV, home-ventilated; STAI-S, State-Trait Anxiety Inventory-State; STAI-T, State-Trait Anxiety Inventory-Trait.

implement social and psychological support for these families.[23,24,27] Our results were similar to those shown by the studies, suggesting that poor perceived social support leads to depression.[28,29]

Meltzer et al.[30] found that caring for a child with underlying chronic diseases had a negative impact on the sleep pattern of the mother due to depression and fatigue. Lack of regular night nursing was also shown to be related to reduced total sleep time and depression, compared to caregivers with regular support. Sleep disruptions and chronic sleep loss during the night may lead to reduced daytime functioning.[31] Additional caregivers can provide care for the patient at night, allowing the mother to sleep and may also reduce the burden of depression and anxiety on the primary caregiver. However, in our study, we were unable to find a significant difference between the levels of anxiety, depression scores, and the presence of another caregiver. This may be related to the small number of our study group.

The BDI and STAI-T levels were found to be significantly better in mothers who retained employment compared to the mothers who stopped working. Since HV patients require full-day attention, main caregivers may tend to give up their jobs.[32–34] A mother who is unable to stop working due to financial concerns seems to have a high level of depression and anxiety because she feels she cannot provide the necessary care for her child.

In a recent study in China the prevalence of anxiety and depression, in general, during the COVID-19 pandemic was found to be approximately 8.3% and 14.6%, respectively, and having self-reported poor health was associated with a high level of anxiety and depression.[11] In our study the depression and anxiety levels in the mothers of HV children were 38.1% and 42.8%, respectively, during this period. Considering that COVID-19 infection could have negative effects on the health of HV children, one may speculate that a consequence of this is a corresponding negative effect on the psychological status of the caregivers.

The health of caregivers is directly related to the health of the patient and to minimize the risk of problems associated with poor health and well-being amongst carers' proper access to adequate support such as special physiotherapy devices, medical supplies, and home-care services is of paramount importance. It is, therefore, essential, as a preventative measure, that caregivers of HV children are routinely screened for mental health and supported by government-funded home-nursing measures.

A limitation of the study is that depression and anxiety levels of the mothers in the control group were not evaluated immediately before the pandemic; the mothers that took part and who constituted the prepandemic evaluation group were those who participated in a cross-sectional study performed 3 years ago in our center.

Some of the patients had been tracheostomised in our hospital and some of them were referred to us after being tracheostomised; it was, therefore, not possible to assess the differences in depression and anxiety levels based on the changing health status of the child.

The medical conditions of the patients and the socioeconomic status of the families were unchanged during the period and the duration of the HV was not found to be related with higher/lower levels of depression; this may suggest these limitations were unlikely

to affect the anxiety and depression levels of the mothers. One of the limitations of using questionnaires is the differences in the literacy levels of participants. To overcome this potential obstacle, our survey was conducted via a telephone call with the mothers, all made by the same physician. Some families, however, may still have found it difficult to be honest or forthcoming with their physician due to fears of being judged or deemed incapable of caring for their children.

In conclusion, the study revealed the high prevalence of impaired psychological health in mothers of HV children. This is the first study that compares depression and anxiety levels in the mothers of HV children with the mothers of healthy peers during COVID-19. Since improving caregiver well-being is directly related to the care and health of the patient, more attention should be paid by the government to the economic, medical, and social support given to the families of HV patients with regard to improving their mental well-being, especially during a pandemic such as the one currently ongoing.

CONFLICT OF INTERESTS
The authors declare that there are no conflict of interests.

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