





Depression, anxiety, and sleep quality of caregivers of children with spinal muscular atrophy

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Abstract

Background: The aim of this study was to evaluate the prevalence of anxiety, depression, sleep, and associated factors in caregivers of children with spinal muscular atrophy (SMA).

Materials and Methods: Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory-State (STAI-S), the State-Trait Anxiety Inventory-Trait (STAI-T), and Pittsburgh Sleep Quality Index (PSQI) were used to assess the anxiety, depression, and sleep quality of the caregivers of children with SMA. Higher scores indicated worse outcome for all three questionnaires.

Results: Fifty-six caregivers of children with SMA were included in the study. Median age of children was 6 (3.2–10) years and mean age of the caregivers was 37.0 ± 6.5 years. Median scores of the BDI, STAI-S, STAI-T, and PSQI were 12 (7.2–17), 35.5 (31–44), 40.5 (35–48), and 7.0 (5.0–10.0), respectively. There was a positive correlation between BDI and PSQI scores ($p < 0.05$). There was a negative correlation between the age of the caregivers and PSQI, BDI, STAI-T scores ($p = 0.01$, $r = -0.341$; $p = 0.006$, $r = -0.364$; $p = 0.003$, $r = -0.395$, respectively). There was a negative correlation between the age of the patients and the PSQI scores of the caregivers ($p = 0.01$, $r = -0.33$). There was a negative correlation between BDI scores and household income ($p = 0.01$, $r = -0.34$).

Conclusion: Caregivers of children with SMA had elevated depression and anxiety levels and they also had decreased sleep quality. Economic and social support resources are needed to help caregivers of those children.

KEYWORDS

anxiety, caregiver, depression, sleep quality, spinal muscular atrophy

1 | INTRODUCTION

Spinal muscular atrophy (SMA) is a progressive neurodegenerative disorder and the leading genetic cause of infant death.¹ Patients with SMA experience muscle weakness that develops into paralysis, including the respiratory muscles and they gradually become physically dependent on their caregivers.²

Having a child with SMA may be a significant burden for the caregivers. Increased responsibilities of handling the child's medical treatments, clinic appointments, and psychosocial difficulties can cause stress for caregivers.³ Children with SMA could require care all day long, especially during intercurrent illnesses. High levels of stress and a lower quality of life of the caregivers may be related to insufficient social support and family resources. Studies that investigated the caregivers of dependent people with chronic diseases showed psychological problems.^{4–6} Anxiety and depression were reported as the most prevalent issues in the caregivers.^{6–8} Depression is a common reaction to grief when there is a diagnosis of a disease with high mortality within the family. Overall health of the caregivers was also found to be poor, which may be linked to their depressive symptoms.⁹ Caregivers' depression and anxiety may also increase as the number of years they have spent caring for patients increases.

A good quality sleep has been shown to be an important component of overall health and well-being, and its deficiency is associated with a variety of disorders.¹⁰ Caregivers of dependent patients with chronic diseases exhibit some impaired sleep features.¹¹ Caregivers of children with SMA may experience poorer sleep quality due to increased sleep disturbances and shorter sleep duration. Sleep disorders in caregivers have been linked to issues such as anxiety, mental distress, financial difficulties, and insufficient support systems.^{12–14} Previous studies showed that caregivers of patients with chronic conditions have cognitive deficits, psychological stress, and depressive symptoms as a result of their sleep problems.^{6,15} Caregivers are more likely to suffer from insomnia than the general population.^{16,17} At least 72% of caregivers of advanced cancer patients experienced moderate to severe sleep disturbances, with a significant reduction in total sleep time.¹⁸ Caregivers of children with neurodevelopmental disorders, such as cerebral palsy, had poorer sleep quality than caregivers of healthy children.¹⁹

There have been a few studies which characterize the mental health of caregivers for children with SMA, but to date, their sleep quality has not been described with validated tools. This aspect of caregiver well-being should be explored to promote discussion of effective solutions.

In Turkey, children with chronic disease care are mainly cared by the families due to the lack of home health care services. The primary aim of this study was to investigate the anxiety and depression levels and sleep quality in primary caregivers of children with SMA. The secondary aim was to evaluate the factors associated with depression, anxiety, and poor sleep quality and the correlation between the study variables and scores of the depression, anxiety, and sleep quality scales.

2 | MATERIALS AND METHODS

2.1 | Patients and study design

This cross-sectional study was conducted on caregivers of children with SMA between July 2021 and January 2022. Caregivers were invited to complete the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory-State (STAI-S), the State-Trait Anxiety Inventory-Trait (STAI-T), and Pittsburgh Sleep Quality Index (PSQI). Surveys were performed via telephone calls by the same physician. Caregivers with a diagnosis of any psychiatric/chronic physical/neurological disease/and/or have another family member who requires special care were excluded from the study.

2.2 | Assessment tools

2.2.1 | Data collection form

The researchers created the data collection form, a detailed interview form consisting of questions about the participants' general information, specifically for the current study.

2.2.2 | The STAI

The STAI is a self-report questionnaire with two subscales (state anxiety and trait anxiety), each with 20 items that assess anxiety levels. The STAI-S scale is used to describe how people feel at a certain time, whereas the STAI-T scale describes how people feel in general. Each issue in the anxiety survey is given a score ranging from 1 to 4. The range of possible scores is 20–80, with higher levels indicating greater anxiety. In the current study, scores ≥ 40 for STAI were accepted as the presence of anxiety.²⁰

2.2.3 | BDI

The BDI was used to assess present depression symptoms based on self-report. It has 21 questions about depressive symptoms, each of which is graded on a scale of 0–3. Each completed questionnaire provided a total score ranging from 0 to 63. Higher scores indicate the existence of higher levels of depression. Mild depression is defined as a score of 11–17; moderate depression is defined as a score of 18–23; and severe depression is defined as a score of 24 or higher.²¹

2.2.4 | PSQI

Buysse et al. developed the PSQI, which has 7 subcomponents and 18 questions.²² Subjective Sleep Quality (one question), Sleep Latency (two questions), Sleep Duration (one question), Sleep

Efficiency (three questions), Sleep Disorder (nine questions), Use of Sleep Medications (one question), and Daytime Dysfunction (two questions) are the seven subscales. Each question is given a score of 0 (no difficulty) to 3 (severe difficulty), with 3 representing the negative extreme. The total score varies from 0 to 21, with higher numbers indicating poor sleep quality. According to earlier studies, poor sleep quality was defined as a total score of 5 or greater.²³

2.3 | Statistics

Statistical analyses were conducted in IBM SPSS version 23.0[®] (SPSS Inc.). $p < 0.05$ was accepted as statistically significant. Categorical variables were reported as frequency percentages. Continuous variables were expressed as mean \pm standard deviation for normally distributed data and median (25th, 75th percentile) for data that were not normally distributed. Nonparametric Mann-Whitney U and χ^2 tests were used for comparison between groups. The Kruskal-Wallis test was used to compare the means. Spearman's correlation analysis was used to evaluate the relationship between various variables.

3 | RESULTS

The study included 56 caregivers of children with SMA. Thirty-nine (69.6%) of the caregivers were female and 17 were male. Thirty-three of the participants were solo caregivers for their children. The demographic data of the caregivers are shown in Table 1.

Thirty-four of the children were SMA type 1. Forty-seven of the patients (83.9%) were on nusinersen treatment. The median duration of home ventilation therapy was 3 (1.2–5.5) years.

Nine children were not attending school even though they were at school age. The demographic data of the patients are shown in Table 2.

The BDI, STAI, and PSQI scores of the caregivers are shown in Table 3. Twenty (35.7%) of the caregivers had mild, five (8.9%) had moderate, and seven (12.5%) had severe depression. State anxiety was present in 20 (35.7%) of the caregivers and trait anxiety was present in 32 (57.1%). The total PSQI scores were >5 in 43 (76.8%) of the caregivers.

There was no association between the type of SMA and the caregiver's PSQI, BDI, and STAI results and also there was no association between the educational status of the caregiver and PSQI, BDI, STAI scores ($p > 0.05$). The proportion of poor sleepers was significantly higher in the employed caregivers ($p = 0.02$). The BDI scores of the caregivers of the patients on nusinersen treatment were significantly higher ($p = 0.04$). There was no difference between the scores of mothers and fathers in any of the questionnaires ($p > 0.05$). No relation was found between the presence of a helper in the care of the child and anxiety, depression, and quality of sleep.

There was a negative correlation between the age of the caregiver and the BDI score ($p = 0.006$, $r = -0.36$). There was a negative correlation between household income and BDI score

TABLE 1 Characteristics of the caregivers.

Demographic data	n = 56
Age of the caregivers, years, mean \pm SD	37.0 \pm 6.5
Occupation, n (%)	
Employed	20 (35.7)
Unemployed	36 (64.3)
Education completed by caregiver, n (%)	
No school completed	3 (5.4)
Elementary/middle school	24 (42.9)
High school	14 (25.0)
University	15 (26.8)
Marital status, n (%)	
Married	55 (98.2)
Divorced	1 (1.8)
Total monthly household income, n (%)	
Under poverty threshold	52 (92.9)
Over poverty threshold	4 (7.1)

($p = 0.01$, $r = -0.34$). There was a positive correlation between BDI and STAI-S, STAI-T, and PSQI scores ($p < 0.05$). The correlation coefficients (r) between the study variables and the scores of the surveys are shown in Table 4.

4 | DISCUSSION

In the current study, we found that the majority of the caregivers of children with SMA had depression and trait anxiety. Sleep quality was poor in caregivers of children with SMA and it improved as the age of the caregiver/patient increased. Depression levels were inversely correlated with the sleep quality scores of the caregivers. We also found that the depressive symptoms of the caregivers of the children on nusinersen treatment were significantly higher.

There is a high probability of developing physical and psychological problems in caregivers of children with chronic diseases especially if they do not receive professional support for the care of the child. A study by von Gontard et al. showed that, when compared with matched controls, the families of children with SMA had high levels of mental stress.²⁴ When the parents were informed about the progress and lack of a permanent cure for SMA, they are distressed. Majority of our study participants were depressive and had trait anxiety supporting the prior studies. Caregivers who are dealing with SMA may feel incapable of problem solving, which can lead to depression and anxiety. Although Ford and Kamerow showed that caregivers of children with SMA type 1 or 2 experience more stress than families of children with SMA type 3, we found no difference in depression, anxiety levels, or sleep quality of parents between the three SMA types.²⁵ This result could be explained by the limited number of SMA type 3 patients in the current study.

TABLE 2 Characteristics of the children.

Age of the children, years, median (25–75 percentile)	6 (3.2–10)
Age of the diagnosis, months, median (25–75 percentile)	5.2 (3.0–19.5)
Female gender, <i>n</i> (%)	29 (51.8)
Type of SMA, <i>n</i> (%)	
Type 1	34 (60.7)
Type 2	12 (21.4)
Type 3	10 (17.9)
Number of siblings, median (25–75 percentile)	2 (1.2–2)
Mobility, <i>n</i> (%)	
Independent movement	13 (23.2)
Uses wheelchair	22 (39.3)
No independent movement	21 (37.5)
Schooling (<i>n</i> = 30, >6 years)	
No education	9 (30)
Home school	6 (20)
Full-time school	15 (50)
Feeding, <i>n</i> (%)	
Oral	36 (64.3)
Nasogastric tube	6 (10.7)
Gastric tube	14 (25)
Home-ventilation, <i>n</i> (%)	
Invasive ventilation	9 (16.1)
Noninvasive ventilation	16 (28.6)
Duration of using home ventilation (years), median (25–75 percentile)	3 (1.2–5.5)
Nusinersen treatment, <i>n</i> (%)	47 (83.9)

Abbreviation: SMA, spinal muscular atrophy.

TABLE 3 The BDI, STAI, and PSQI scores of the caregivers.

BDI, median (25–75 percentile)	12 (7.2–17)
STAI-S, median (25–75 percentile)	35.5 (31–44)
STAI-T, median (25–75 percentile)	40.5 (35–48)
Total PSQI score, median (25–75 percentile)	7.0 (5.0–10.0)

Abbreviations: BDI, Beck Depression Inventory; PSQI, Pittsburgh Sleep Quality Index; STAI-S, State-Trait Anxiety Inventory-State; STAI-T, State-Trait Anxiety Inventory-Trait.

Nusinersen was the first available medication for people with SMA altering the natural course and brought hope to caregivers.²⁶ In the NURTURE study, which included 25 presymptomatic SMA1 patients, early initiation of nusinersen at younger than 6 weeks of age

TABLE 4 Correlation coefficient (*r*) between the study variables and scores of the BDI, STAI-S, STAI-T, and PSQI.

	STAI-S	STAI-T	PSQI	BDI
Age of the patient	−0.11	−0.18	−0.33	−0.16
Age of the caregiver	−0.23	−0.39	−0.34	−0.36
Number of siblings	−0.09	−0.01	−0.17	−0.12
Household income	−0.15	−0.23	−0.15	−0.34
Duration of using home ventilation	−0.25	−0.19	−0.23	−0.39

Note: Bold *r* values: *p* < 0.05.

Abbreviations: BDI, Beck Depression Inventory; PSQI, Pittsburgh Sleep Quality Index; STAI-S, State-Trait Anxiety Inventory-State; STAI-T, State-Trait Anxiety Inventory-Trait.

resulted in no need for permanent ventilation at a median age of 26 months.²⁷ In a study conducted in our department, we showed that the median age of initiation of nusinersen was late (3.7 months) even in patients who started the treatment before 6 months of age.²⁸ So the depression of the caregivers of children receiving nusinersen may be related with delay in initiation of treatment. Caregivers of patients with chronic diseases have a shorter duration of sleep than noncaregivers, according to the prior research.^{29,30} Sleep abnormalities can affect daytime functioning, increase the risk of psychiatric problems, and exacerbate the progression of chronic illnesses.^{25,31,32} Meltzer et al. showed that, due to depression and exhaustion, caring for a child with chronic conditions had a significant impact on the mothers' sleep pattern.³³ The PSQI, a self-reported sleep quality questionnaire, is the most widely used measure for determining sleep quality. A study from our center revealed that patients with bronchiectasis have disturbed sleep associated with severity of disease.³⁴ McKibbin et al. has shown that caregivers of patients with dementia had moderate to severe sleep disturbance scored by PSQI.³⁵ In another study among caregivers of patients with Duchenne muscular dystrophy it has been shown that over 60% of the caregiver-mothers had impairment of their sleep, particularly longer sleep latency.³⁶ The current study revealed that 76.8% of caregivers of children with SMA had poor sleep quality. Negative thoughts or distress are common among family caregivers, and these feelings usually manifest themselves at night, leading to disturbed sleep.³⁷ Considering the scarcity of studies on the sleep quality of caregivers of children with SMA, more studies are required in this field.

As technology develops, the number of families caring for technology-dependent children at home is growing. A research that used the PSQI has shown that caregivers of technology-dependent children are poor sleepers.³⁸ Sleep deprivation may occur in caregivers of children using home ventilation as a result of having to turn on the device or turn off the alarms. In our sample, 44.6% of children were on home ventilation and there was no correlation in terms of home ventilation duration and sleep quality. In contrast, a research on Duchenne patients revealed that duration of noninvasive ventilation was inversely related with poor sleep quality (25 vs. 63

months).³⁶ We also could not find an association between children's home ventilation duration and the sleep quality of the caregiver. The current study included children with SMA and SMA typically progressed more severely than Duchenne disease. In addition, the majority of the patients included in the study were SMA type 1 which has the most severe course. Therefore the sleep quality of the caregivers of the current study may not have changed over time due to the failure to adapt to the severity of the disease.

The sleep quality was significantly lower in employed caregivers. As being strictly dependent on certain working hours might cause shorter sleep duration, which may cause deterioration in the sleep quality. Additionally, most of the caregivers had to wake up frequently at night to take care of the children with SMA, which may be the main reason causing an impairment on the sleep quality. Another important factor affecting the depression levels was lower income levels.

In our study, it was observed that mothers of children with older age had better sleep quality. Our result was consistent with the study of Nozoe et al.³⁶ that could be explained with the fact that care demands diminish as children get older.

Most of the families were living under the poverty limits according to Turkish standards and not surprisingly, depression levels were higher in lower household income groups. Sleep quality was not different in different income levels.

A limitation of the study is that questionnaires were administered to one of the parents of children with SMA. Mental health may differ between mothers and fathers. However, in our study, we did not observe any difference in anxiety and depression levels and sleep quality in terms of responders' gender. In addition to that parental obstructive sleep apnea symptoms were not evaluated.

In conclusion, depression, trait anxiety, and poor sleep are common in caregivers of children with SMA. It has been shown that poor sleep quality is associated with high depression levels. Therefore, the depression, anxiety, and sleep quality of caregivers of children with SMA should be evaluated regularly and psychological support should be provided to these parents if needed.

AUTHOR CONTRIBUTIONS

Almala Pinar Ergenekon: Conceptualization; investigation; writing—original draft; methodology; visualization; software; formal analysis; supervision. **Zeynep Gümüş:** Investigation; writing—original draft; methodology; formal analysis; software; conceptualization. **Cansu Yilmaz Yegit:** Investigation; writing—original draft; formal analysis. **Muruvvet Cenk:** Investigation; writing—original draft. **Aynur Gulieva:** Investigation; writing—original draft. **Mine Kalyoncu:** Investigation; writing—original draft. **Merve Selcuk:** Investigation; writing—original draft. **Seyda Karabulut:** Visualization; software; formal analysis. **Gulten Ozturk:** Methodology; writing—review and editing. **Ela Erdem Eralp:** Writing—review and editing; investigation; writing—original draft; formal analysis; supervision. **Olca Unver:** Writing—review and editing; writing—original draft; investigation; formal analysis; supervision. **Bulent Karadag:** Investigation; writing—original draft; validation; writing—review and editing; supervision. **Yasemin Gokdemir:**

Supervision; writing—review and editing; writing—original draft; investigation; validation; formal analysis; software.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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