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Exploring the Relationship between Maternal Anxiety, Sleep Disturbances, and Family Quality of Life in Children with Cerebral Palsy

Nihal Serdengeçti[1], Zeynep Kılıç[2], Gürkan Tarçın[3], Zeynep Seda Albayrak[4]

[1]Department of Child and Adolescent Psychiatry Clinic, Yüksekova State Hospital, Hakkari, Türkiye
[2]Department of Pediatrics Clinic, Yüksekova State Hospital, Hakkari, Türkiye
[3]Department of Pediatric Endocrinology Clinic, Adana City Training and Research Hospital, Adana, Türkiye
[4]Department of Child and Adolescent Psychiatry Clinic, Koç University Hospital, Istanbul, Türkiye

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Abstract

Objective: Cerebral palsy (CP) is a chronic condition that can have a significant impact on the quality of life (QoL) of patients and their families. A child's sleep disturbances and maternal anxiety are common issues in CP; however, their impact on family QoL is not fully understood. This study aimed to investigate the relationship among child's sleep disturbances, maternal anxiety levels, and family QoL in children CP.

Methods: This study included 58 children with CP and 63 typically developing (TD) peers matched for age and sex, along with their mothers. We used the Sleep Disturbance Scale for Children, Beck Anxiety Inventory, and Beach Center Family Quality of Life Scale to assess children's sleep problems, maternal anxiety, and family QoL, respectively. Regression analysis was conducted to identify other factors that could affect the family QoL.

Results: Children with CP had more sleep disturbances, lower family QoL, and higher levels of maternal anxiety compared to their TD peers. Moreover, maternal anxiety was significantly related to family QoL and child's sleep disturbances in children with CP. Regression analysis revealed that other factors such as age, sex, motor function, having a diagnosis of epilepsy, and cognitive level did not affect family QoL in children with CP.

Conclusion: Addressing children's sleep disturbances and mother's anxiety can be important for the family QoL of children with CP. Interventions focused on these issues can help this population, but further research is needed to develop effective strategies for enhancing the well-being of children with CP.

Keywords: Cerebral palsy, sleep disturbances, maternal anxiety, family quality of life

Introduction

Cerebral palsy (CP) is a cluster of neurological disorders that impair movement, balance, and posture, and is the leading cause of motor disability in childhood, attributed to non-progressive disorders of the developing fetal or infant brain that cause limitation in activity.[1] According to the current classification system, patients with CP are categorized as spastic (increased muscle tone), dyskinetic (involuntary movements), or ataxic (loss of motor coordination).[2] Cerebral palsy frequently co-occurs with other pathologies, such as epilepsy, cognitive impairment, and hearing and vision problems.[2]

Although cerebral palsy is currently incurable, certain interventions can improve the quality of life (QoL) of patients and their families. Before implementing interventions, it is important to identify the factors that may affect family QoL. While individual and caregiver QoL have been frequently studied, there are fewer approaches that focus on the family as a whole.[3] Having a child with a disability in the family increases the burden on the primary caregiver,[4] making it difficult to give equal attention to other family members and negatively impacting the caregiver's mental health.

In addition to symptom severity and comorbidities, other factors such as sleep may influence the QoL of children with CP.[5] Lelis et al. recently reported a higher incidence of sleep disorders among children with CP than typically developing (TD) children.[6] Although sleep is crucial for the healthy development of children, it is frequently overlooked in clinical practice and may not always be addressed during routine doctor visits.[7] In a study conducted in Malaysia, sleep disturbances in children with CP were shown to influence family functioning.[8] In Lang et al. study, nighttime attention, children's sleep problems, and caregivers' sleep quality were found to be significant in explaining caregiver anxiety.[9] Despite the limited research on the direct association between a child's sleep problems and a mother's anxiety symptoms, it is reasonable to speculate a potential link, given that anxiety, akin to depression, is an internalizing disorder.

When caring for children with CP, caregiver burden and mental health are important factors to consider. According to a meta-analysis that included parents of children with disabilities, including CP, anxiety and depression scores were higher compared to parents of healthy children.[10] Additionally, symptoms of anxiety and depression in parents were directly proportional to the caregiver burden.[4] While some factors associated with anxiety and depression, such

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Corresponding author: Nihal Serdengeçti, Department of Child and Adolescent Psychiatry Clinic, Yüksekova State Hospital, Hakkari, Türkiye
e-mail: nihalserdengecti@gmail.com
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as the child's mental disability, gender of the primary caregiver parent, and poor economic status, cannot be changed, other factors such as lack of social support, parental health status, and loneliness can be improved.[11]

We aimed to investigate factors that may affect family QoL by first examining those that are related to QoL in children with CP and also their parents. The goal of this study was to investigate the relationship between a child's sleep disturbances, maternal anxiety levels, and family QoL in children with CP. The first hypothesis was that the CP group would experience more sleep disturbances, have worse family QoL, and have higher levels of maternal anxiety compared to their healthy group. In addition, we aimed to determine the correlations and associations among sleep disturbances, maternal anxiety levels, and family QoL in both groups.

Methods

This study used a descriptive cross-sectional design. Ethical approval was obtained from the Sağlık Bilimleri University Van Research and Training Hospital Research Ethics Committee (Approval no: 2023-01-14, Date: January 4, 2023). Written informed consent was obtained from the parents of the children who participated in the study and from children with appropriate cognitive level.

Selection of the Participants

Children with CP aged between 5 and 18 years, accompanied by their mothers, were enrolled in a pediatric outpatient clinic for participation in the study between January and April 2023 (Figure 1). The exclusion criteria were patients who did not consent to participate in the study, patients with incomplete forms, individuals with a sibling having a disability, and patients whose primary caregiver was not their mother or whose mother had deceased or was affected by a serious disease (cancer, etc.).

For the control group, we employed a matched sampling approach. The inclusion criteria for the control group comprised the absence of any chronic illness, no prior referrals to psychiatry, having a mother as the primary caregiver, and voluntary participation in the study. Participants failing to meet these criteria were excluded. Eligible patients identified in the outpatient pediatric clinic of the same hospital during the same time period were referred to the child and adolescent psychiatry outpatient clinic to participate in the study. Those who agreed to take part and presented themselves at the outpatient child and adolescent psychiatry clinic were included in the study.

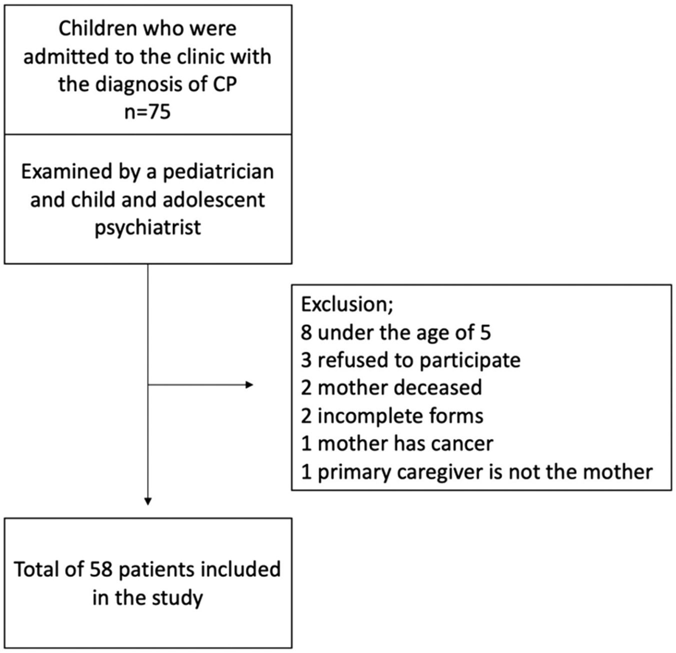

Figure 1. Selection of the study participants.

All participants underwent a comprehensive evaluation conducted by both a pediatrician and a child and adolescent psychiatrist. Patients were divided into 5 subgroups by evaluating their cognitive level with the golden standard psychiatric examination, which evaluates difficulties in conceptual, social, and practical areas of living, and when necessary, supported with psychometric tests appropriate for their age and educational background.

Measurement Tools

Sociodemographic Questionnaire

Mothers completed a form prepared by the researchers that included relevant information about their child's age, number of siblings, family education, health status, and income level.

Cognitive Assessment

According to the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*), clinicians are advised to combine clinical assessment and standardized intelligence testing in determining cognitive level and diagnosing intellectual disability, prioritizing adaptive functioning over relying solely on IQ test scores.[12] In this study, the family and the child were evaluated in the clinical interview and the child's functionality across three domains (conceptual, social, and practical) was assessed. For standardized intelligence testing, children below 6 years of age were administered the Ankara Developmental Screening Inventory,[13] while the population over 6 years of age was administered the Kent EGY or Wechsler Intelligence Scale for Children (WISC-R) according to their adaptive skills.[14] Given the use of 3 different tests, IQ scores were excluded from the statistical analysis.

Gross Motor Function Classification System

Gross motor function levels of the children were categorized into 5 groups using the Gross Motor Function Classification System (GMFCS).[1] The GMFCS is a widely used system that classifies the gross motor function of individuals with cerebral palsy, helping to describe their functional abilities and limitations related to gross motor skills. Level 1 indicates the highest level of mobility, with subsequent levels (2-5) representing a gradual deterioration in gross motor function.

Beck Anxiety Inventory

The Beck Anxiety Inventory (BAI) was used to evaluate the level of anxiety symptoms in mothers. The self-report scale was originally developed by Beck to assess anxiety symptoms experienced during the previous week.[15] A validation study by Ulusoy et al.[16] reported a Cronbach's α value of 0.93 for the Turkish population. The scale comprises a Likert-type scale ranging from 0 to 3, with a total score range of 0-63, with higher scores indicating greater severity of anxiety symptoms.

Beach Center Family Quality of Life Scale

The Beach Center Family Quality of Life Scale (BCFQoL) scale was developed by the Beach Center on Disability at the University of Kansas to measure the QoL of families of children with intellectual and developmental disabilities.[17] Meral et al.[18] conducted a validity and reliability study of the Turkish version of the scale and reported Cronbach's α value of 0.92. The scale is rated on a Likert scale ranging from 1 to 5, with a total score ranging from 25 to 125 and 5 domains. A higher score indicates better family quality. In our study, we used only 4 of the most relevant domains (family interaction, emotional/well-being, parenting, physical/material well-being), so the total score was therefore between 21 and 105.

Sleep Disturbance Scale for Children

In our assessment of sleep problems over the past 6 months, we used the Sleep Disturbance Scale for Children (SDSC) scale. This scale, developed by Bruni et al.,[19] comprises 24 questions and several subscales, namely, disorders of initiating and maintaining sleep, sleep breathing disorders, disorders of arousal, sleep–wake transition disorders, disorders of excessive somnolence, and sleep hyperhidrosis. The scale is rated on a Likert scale ranging from 1 (never) to 5 (always), with a total score between 24 and 120, and a higher score indicating more sleep problems. The Cronbach's α coefficient was 0.81 in the Turkish validity and reliability study, with a cutoff value of 34 and a sensitivity and specificity of 0.82 and 0.67, respectively.[20]

Beck Anxiety Inventory, BCFQoL, and SDSC were completed by the mothers of the children in our study. In cases where clarification was required or if any points were unclear, clinicians were available to assist and provide support during the completion of the scales.

Statistical Analysis

The Statistical Package for Social Sciences version 22.0 software (IBM Corp.; Armonk, NY, USA) was used for statistical analyses. Data distribution was evaluated using histograms, quantile–quantile plots, skewness, and kurtosis. Sleep Disturbance Scale for Children and BCFQoL scores followed a parametric distribution, the BAI scale followed a nonparametric distribution. In comparing two independent groups, the appropriate statistical tests were selected based on the distribution of the data. Specifically, the Student's *t*-test was utilized for data with parametric distributions, while the Mann–Whitney *U*-test was employed for data with nonparametric distributions. Additionally, Pearson's correlation test was applied to examine the relationship between scale scores in parametric distributions, whereas Spearman's correlation test was utilized for nonparametric distributions. The Pearson chi-square test was used to determine the association between categorical variables. A multiple linear regression model was constructed to identify the determinants of the BCFQoL total score. Statistical significance was set at $P < .05$.

After completing the study, a post hoc power analysis using G*Power 3.1 was conducted to assess the effect size. Considering the difference in the total scores between 2 groups, a power of 99% at an α level of 5% was obtained for each of the 3 scales.

Results

Characteristics of Participants

A total of 58 out of 75 children with CP who were admitted to the pediatric outpatient clinic were included in the study (Figure 1). The control group comprised 63 children who were matched in terms of gender and age and did not have any previous psychiatric complaints or chronic diseases. No significant differences in sociodemographic characteristics were observed between the 2 groups. The characteristics of the study group can be found in Table 1. Out of the 58 children with CP, 17 of them had epilepsy (29.3%).

Table 1. Participant Demographics and Characteristics

	The CP Group n = 58	The TD Group n = 63	P
Age (years) mean ± SD	10.3 ± 4.4	9.9 ± 3.6	.585*
Maternal ae (years) mean ± SD	39.55 ± 8.0	37.81 ± 7.5	.222*
Paternal age (years) mean ± SD	43.04 ± 8.8	41.32 ± 7.9	.271*
Sex (n, %)			
Male	34, 58.6	32, 50.7	.388**
Female	24, 41.4	31, 49.3	
Maternal education (n, %)			
Below high school	52, 89.1	50, 79.3	.120**
High school and above	6, 10.1	13, 20.6	
Paternal education (n, %)			
Below high school	35, 60.3	37, 58.7	.857**
High school and above	23, 39.6	26, 41.2	
CP subgroups (n, %)			
Spastic	44, 75.8	NA	NA
Dyskinetic	8, 13.7		
Ataxic	6, 10.5		
GMFCS groups (n, %)			
1	2, 3.4	63, 100	
2	14, 21.1	–	NA
3	11, 18.9	–	
4	21, 36.2	–	
5	10, 17.2	–	
Cognitive levels (n, %)			
IQ above 85	12, 20.6	NA	NA
IQ between 70 and 85	6, 10.3		
Mild intellectual disability (ID)	13, 22.4		
Moderate ID	12, 20.6		
Severe ID	15, 25.8		

CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; IQ, intelligence quotient; NA, non-applicable; SD, standard deviation; TD, typically developing.
*Student's *t*-test.
**Pearson's chi-square test.

Comparison of the Scales between the Groups

When comparing child's sleep disturbance scores (SDSC), it was found that children with CP had significantly higher scores than the TD group in the total and subscales ($P < .001$), except for the disorders of arousal ($P = .511$) and sleep hyperhidrosis ($P = .094$) subscales (Table 2). In the CP group, 52 out of 58 patients (89.6%) scored above the cut-off on the SDSC, while this rate was observed in 27 out of 63 patients (42.8%) in the TD group ($P < .001$).

The family quality of life (BCFQoL) scores of children with CP were lower in all subscales compared to the TD group. Additionally, the anxiety scores of mothers with children with CP were significantly higher than those of mothers in the TD group (Table 2).

Factors Affecting BCFQoL Scores

Correlation analyses were conducted to examine the relationship among SDSC total score, BCFQoL total score, and BAI total score in 2 separate groups. As shown in Table 3, in the CP group, there was a moderate negative correlation of BCFQoL total score with both SDSC and BAI total score ($P < .001$, $R = -0.487$ and $P < .001$, $R = -0.491$, respectively). Additionally, a strong positive correlation was observed between the BAI and SDSC total score

Table 2. Comparison of the SDSC, Beach Center Family QoL, and Beck Anxiety Inventory Scale Scores between the Groups

	The CP Group n = 58 Median (Minimum–Maximum)	**The TD Group n = 63 Median (Minimum–Maximum)**	***P***
SDSC			
Disorders of initiating and maintaining sleep	18 (9-32)	12 (7-23)	**<.001**
Sleep breathing disorders	5 (3-15)	3 (3-11)	**<.001**
Disorders of arousal	4 (3-15)	4 (3-9)	.511
Sleep–wake transition disorders	9 (4-18)	6 (4-13)	**<.001**
Disorders of excessive somnolence	9 (5-24)	2 (2-17)	**<.001**
Sleep hyperhidrosis	4 (2-12)	5 (2-11)	.094
Total	50 (28-99)	36 (22-63)	**<.001**
Beach Center Family QoL			
Family interaction	24 (10-30)	26 (14-30)	**<.001**
Parenting	24 (9-29)	27 (16-30)	**<.001**
Emotional/Well-being	14 (7-20)	16 (7-20)	**.001**
Physical/Material well-being	13 (5-22)	18 (8-25)	**<.001**
Total	75.5 (39-97)	87 (47-105)	**<.001**
Beck Anxiety Inventory total score	13.5 (0-55)	6 (0-47)	**<.001**

Mann–Whitney *U* test. Values in bold indicate statistical significance.
CP, cerebral palsy; QoL, quality of life; SDSC, Sleep Disturbance Scale for Children; TD, typically developing.

Table 3. Correlation Analysis of Scale Relationships within CP and TD Groups

			1. SDSC Total	**2. BCFQoL Total**
The CP group n = 58	1. BCFQoL total	*R*	−.487	–
		P	**<.001**	–
	2. BAI total	*R*	.712	−.491
		P	**<.001**	**<.001**
The TD group n = 63	1. BCFQoL total	*R*	−.263	–
		P	**.037**	–
	2. BAI total	*R*	.606	−.178
		P	**<.001**	.163

Spearman correlation analysis. Values in bold indicate statistical significance.
BCFQoL, Beach Center Family Quality of Life; BAI, Beck Anxiety Inventory; CP, cerebral palsy; SDSC, Sleep Disturbance Scale for Children; TD, typically developing.

($P < .001$, $R = 0.712$). In the TD group, there was a moderate positive correlation between the SDSC and BAI total score ($P < .001$, $R = 0.606$), and a weak negative correlation between the BCFQoL and the SDSC total score ($P = .037$, $R = -0.263$). There was no significant correlation between the BCFQoL and BAI total score in TD children ($P = .163$, $R = -0.178$). There was also no significant correlation analysis between age and BCFQoL scores ($P = .905$, $R = 0.016$).

In the CP group, a multiple linear regression model was established using sex, age, having a diagnosis of epilepsy, cognitive level, and GMFCS level as variables to identify the factors that influence the BCFQoL total score. However, none of these variables demonstrated a significant effect on the BCFQoL total score ($P = .693$).

Discussion

The results of this study indicated that children with CP exhibited significantly greater sleep disturbances and higher levels of maternal anxiety, along with lower levels of family QoL compared to TD children. Moreover, the study revealed a remarkable correlation among these 3 factors in children with CP.

In line with our study, a recent meta-analysis has reported higher rates of sleep disturbances in children with CP compared to TD children, with rates ranging between 26.9% and 72.1% of children with CP experiencing one or more sleep disorders.[21] In our study, we found an even higher rate of sleep disorders (89.6%) compared to the literature, which may be attributed to the fact that our study was conducted in a rural area with low socioeconomic status and limited access to health facilities. No significant difference was found in the disorders of arousal and sleep hyperhidrosis subscales. In the study conducted by Horwood et al. in Canada, in which sleep disorders were screened between the ages of 6-12 in children with CP using SDSC, the most common sleep problem was found to be disorders of initiation and maintenance of sleep (32.9%), while the rate of sleep hyperhidrosis and disorders of arousal was found to be 8.7% and 7.1%, respectively.[22] In addition to the high rates of sleep disorders in CP, comorbidities such as epilepsy and medications may negatively affect the rate of sleep disorders.[23] It has been shown that 15%-55% of children with CP have an additional diagnosis of epilepsy and up to 50% of the children continue to have seizures despite the use of antiseizure medication.[24] In our sample, the rate of epilepsy comorbidity was 29.3%.

The burden of caring for a child with CP may contribute to elevated anxiety levels in mothers. Studies have shown that long-term caregiving and restricted social activities can increase maternal anxiety and stress.[25] Additionally, there is a positive correlation between caregiver burden and maternal anxiety and depression.[4] Examination of parental sleep quality revealed a detrimental impact, which may negatively affect mothers' mental health.[7,26,27] In TD children, maternal mental health has been found to be associated with both sleep duration and sleep problems in children.[28] Lang et al. showed that the child's sleep problems had a significant role in explaining caregiver anxiety in children with CP.[9] Wayte et al. identified a positive correlation between maternal depression scores and sleep problems in children.[27] Therefore, it is likely that there exists a bidirectional relationship between high levels of maternal anxiety and sleep disturbances in children with CP, suggesting that both factors can mutually influence each other in a negative manner.

When comparing family QoL between groups, we observed that the CP group had lower scores in all domains. A study by Zuculo et al. provides evidence that children with CP experience lower

QoL than healthy children across multiple areas. The study also highlights that sleep disturbances can lead to behavioral changes that may impact the overall well-being of individuals with CP.[29] Boldyreva et al. demonstrated that adolescents diagnosed with CP and having an IQ score above 70 experienced impaired QoL in 6 out of 10 domains.[30] The inclusion of children at various cognitive levels in our sample might have contributed to impairments in even more domains; however, since IQ scores were not included in the analysis, we were unable to examine this relationship. Another study examining the factors influencing family life in children with CP revealed that higher levels of motor independence and having more siblings were associated with a positive effect.[31] Previous studies show that anxiety symptoms in mothers are associated with the proxy-reported QoL of their children.[32,33] However, the relationship between maternal anxiety symptoms and family QoL has not been previously examined.

Sex, age, cognitive, and GMFCS level did not collectively explain a substantial portion of the variance in the BCFQoL total score in the CP group. Gross Motor Function Classification System levels[34] and conditions affecting mobility such as scoliosis[5] and cognitive level[34] have been shown to have a negative effect on individual QoL. In our study, GMFCS did not have a significant effect on family QoL. However, it is important to note that our study focused on family QoL rather than individual QoL, which may explain the lack of significance in this context. Age and sex were not associated with QoL in a similar way to other studies.[5,8] Reddihough et al.'s study showed that rare or less than weekly seizures did not affect QoL while more than weekly seizures negatively affected.[5] The heterogeneity of our group in relation to epilepsy severity and antiseizure medication usage might have contributed to the observed insignificance in our results.

Our study provides valuable insights into the factors influencing family QoL in families with children with CP. Managing sleep disorders is critical for both the child and the family but is often frustrating due to the persistent nature of the problem. Clinicians should keep in mind to ask about sleep in children with CP and consider recommending strategies such as sleep hygiene as an initial intervention. If sleep hygiene alone fails, it should be combined with pharmacologic management.[35] If needed, a referral for further assessment should be offered. In addition to health professionals working with children with special conditions such as CP, school staff and rehabilitation educators can be informed about the importance of sleep and parental support. Implementing preventive interventions, such as offering comprehensive sleep hygiene training to caregivers of children diagnosed with CP, alongside routine assessments of sleep quality through questionnaires during periodic examinations can enhance overall care and well-being.

Similarly, it is essential to assess the mental well-being of mothers, offering support for anxiety management and family support services where necessary. Also, policymakers can develop policies to integrate mental health specialists into home care teams to enhance support for families. These policies should promote the integration of mental health services into the care continuum for families, acknowledging the considerable emotional burden on caregivers and emphasizing the necessity of comprehensive support systems. In summary, a holistic strategy including customized interventions, collaborative teamwork across disciplines, policy backing for community-centric initiatives, and cohesive mental health services is essential for enhancing the welfare and QoL of children with CP and their families. Future research can contribute to a deeper understanding of these aspects, emphasizing the significance of multidisciplinary collaboration.

Limitations

There are a few limitations that should be taken into consideration when interpreting our results. First, the design of the study does not allow a demonstration of a cause-and-effect relationship. Secondly, our examination was limited to mothers only, although it should be noted that mothers served as the primary caregivers within our sample. However, it is worth noting that this exclusion may overlook potential differences in caregiving dynamics across different cultural parental roles, warranting further exploration in future research. Furthermore, IQ scores were not included in the analysis due to the use of different cognitive tests among individuals in the group, so we were not able to explore the potential influence of cognitive abilities on the observed outcomes. It was also not possible to compare between CP types due to the small number of subgroup sizes. Finally, the generalizability of the study may be limited due to small group sizes and since it was conducted in a single center in a rural area with limited facilities. It was not possible to reach all children with CP due to the mountainous nature of the region and transportation difficulties. Nonetheless, this aspect can be regarded as a strength since children in this region receive fewer examinations compared to those residing in metropolitan areas.

Conclusion

In conclusion, our study highlights the importance of considering the impact of a child's sleep disturbances and maternal anxiety on family QoL in children with CP. Our findings indicate that children with CP experience more sleep problems and have lower family QoL compared to TD peers. Furthermore, mothers of children with CP had significantly higher anxiety levels, which was found to be significantly related to family QoL in children with CP. These results suggest that interventions aimed at reducing child's sleep disturbances and mothers' anxiety may help to improve family QoL in children with CP. Future research should focus on developing and implementing effective interventions to improve the QoL of both children with CP and their families. Patients, their families, and other caregivers should be informed and closely monitored about the child's sleep and maternal anxiety.

Ethics Committee Approval: Ethics committee approval was received for this study from the Ethics Committee of Sağlık Bilimleri University Van Research and Training Hospital (Approval no: 2023-01-14, Date: January 4, 2023).

Informed Consent: Written informed consent was obtained from the parents of the children who participated in the study and from children with appropriate cognitive level.

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