The Turkish Journal of Pediatrics 2025; 67: 522-532
https://doi.org/10.24953/turkjpediatr.2025.5793

Original Article

Spastic cerebral palsy and quality of life in children aged 6-12 years: exploring key associated factors

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ABSTRACT

Background. Children with cerebral palsy (CP) may experience epilepsy and challenges with movement, posture, cognition, and musculoskeletal development, which can impact their quality of life (QOL). In this study, we investigated the relationship between demographic and clinical variables as well as QOL in children with spastic CP.

Methods. Children aged 6 to 12 years with CP who were followed-up at our tertiary center were included in this cross-sectional study, regardless of the cause. They were categorized into groups based on their gestational age, motor function levels, accompanying conditions such as epilepsy and intellectual disability, and demographic variables, including mothers' education and income levels. Subsequently, the QOL scores of these groups were compared. Among the 9-12 age group, those with sufficient intellectual capacity completed the QOL questionnaire by both the mothers and patients themselves. The Children's Sleep Habits Questionnaire (CSHQ) was evaluated and compared with the QOL scores of the patients.

Results. A total of 71 patients were included in the study (42 males, 59%). Children whose mothers were more educated and had higher in income level, who were ambulatory with hemiplegia, and did not have epilepsy had significantly better QOL scores. Those with better CSHQ scores were found to have significantly better QOL scores. Additionally, the responses of mothers and patients within the 9-12 age group were highly compatible.

Conclusion. Children with CP face challenges impacting their daily lives and overall QOL. Our study identified factors linked to the QOL of children with spastic CP and showed that their integration into CP management could enhance their well-being.

Key words: cerebral palsy, epilepsy, quality of life, sleep disorder.

Cerebral palsy (CP) is a neurological condition characterized by motor and postural impairments that result from a non-progressive brain injury in the fetal or infantile stage of development.[1] This condition often leads to limitations in physical activity, and it frequently accompanies sensory, cognitive, communication, and behavioral difficulties, as well as epilepsy and secondary musculoskeletal problems.[2]

The World Health Organization Quality of Life (WHOQOL) Group defines quality of life as an individual's personal perception of their position in life, taking into account their cultural and value systems, goals, expectations, standards, and concerns.[3] Various scales are used to assess quality of life (QOL) in children with CP. The first questionnaire designed for this purpose is Cerebral Palsy Quality of Life

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Received 16th Jan 2025, revised 22nd Mar 2025, 26th Apr 2025, 8th Jun 2025, accepted 10th Jun 2025.

for Children (CPQOL-Child), and it involves domains for both children and caregivers.[4]

The CPQOL-Child questionnaire measures a child's well-being rather than their ill-being. Atasavun Uysal et al.[5] confirmed the reliability and validity of this questionnaire by translating it into their native language of Turkish for both the caregiver and child versions. Although there are several studies reporting poorer QOL in children with CP, limited number of studies comprehensively evaluate the factors affecting quality of life alongside all the neurological variables of patients.[6-9]

The most commonly observed form of CP is the spastic type, which can exhibit a wide range of clinical manifestations and may be accompanied by coexisting disorders. Thus, our research concentrated on children with spastic CP. We posited that the QOL for children with CP is not uniform. With this premise in mind, we intended to investigate the relationship between these factors and quality of life of children with CP by examining their clinical and demographic characteristics, including sociocultural factors, the distribution of spasticity, motor functions, intellectual levels, and comorbid conditions such as epilepsy, autism, and sleep disorders. Our secondary aim was to compare parents' and children's perspectives on QOL.

Materials and Methods

Patients and data collection

We planned a cross-sectional study between January 2020 and March 2021 at our tertiary center. Data regarding the QOL of the patients were collected by using CPQOL-Child. The questionnaire was administered during face-to-face appointments of the patients who visited our child neurology outpatient clinic for their regular follow-up. Demographic features including birth weight, gestational age, income and education levels of the parents were reviewed, and the Children's Sleep Habits Questionnaire (CSHQ) was also completed. Data of clinical and laboratory findings were obtained from their medical records, retrospectively.

We included the patients aged 6-12 years with spastic CP whose follow-up duration was longer than 2 years, whose height, weight, and body mass index (BMI) were within the normal limits, and who had a caregiver who was knowledgeable and available to provide information required for the QOL assessment. On the other hand, those who had not undergone proper brain magnetic resonance imaging (MRI), those for whom appropriate metabolic, genetic, and other differential diagnostic evaluations had not been completed, and those who had received botulinum toxin A injection or underwent any surgical procedure in the prior 6 months were excluded from the study.

The study was approved by institutional review board of Istanbul University-Cerrahpasa, Cerrahpasa Medical School (08/07/20-29430533-604.01-01-86126). The study complied with the recommendations of the Declaration of Helsinki for human biomedical research.

The classification of demographic data

Patients were grouped based on their birth weight into normal (2,500 g and above), low (2,500-1,500 grams), and very low (less than 1,500 g). Patients born at 37 weeks or later were classified as term, whereas those born before 37 weeks were classified as premature.

Since all of the patients' caregivers were mothers, the mothers were interviewed. Their age at the time of childbirth and educational level were recorded. Primary or elementary school graduates were categorized as low, while high school and university graduates were classified as high levels of education.

Each year, the Turkish government establishes a minimum monthly income to determine the poverty and hunger threshold. In our study, children's families were classified based on

income: Those below the hunger threshold were determined as low-income, between the hunger and poverty thresholds as medium-income, and above the poverty threshold as high-income groups.

The classification of cerebral palsy

Patients were classified into different groups based on the specific pattern of their spasticity, which included spastic quadriplegia, spastic diplegia, and spastic hemiplegia. The functional status of the patients was evaluated using the Gross Motor Function Classification System (GMFCS) and Bimanual Fine Motor Function (BFMF) classification systems.[10,11] By categorizing patients according to the severity levels of both functions, a better understanding of their motor skills was achieved. Specifically, patients with GMFCS and BFMF levels 1, 2 and 3 were grouped as having mild to moderate motor impairment, while those with GMFCS and BFMF levels 4 and 5 were grouped as having severe motor impairment.

Cerebral palsy associated disorders

In addition to clinical examinations, the Wechsler Intelligence Scale for Children-Revised (WISC-R) test was administered to assess the intellectual level and cognitive capacity of all patients. Patients with a WISC-R score of 70 and above were considered to have a normal intellectual level and cognitive capacity, while the others were defined as having intellectual disability and insufficient cognitive ability. DSM-V criteria were used to diagnose autism.[12] All patients were administered a one-hour wake-sleep video electroencephalography (EEG) examination, during which the 10/20 international electrode placement system was used to record EEG activity. Patients were assessed retrospectively for epilepsy diagnosis based on the current guidelines established by the International League Against Epilepsy (ILAE).[13]

Sleep disturbances

CSHQ, which is already shown to be valid and reliable in children living in Türkiye was used to assess whether the patients had sleep disturbances.[14,15] CSHQ is a parent questionnaire consisting of 33 multiple-choice and three open-ended questions. In addition to bedtime, morning wake-up time and total daily sleep duration, there are eight subscales reflecting different sleep domains in the questionnaire as follows: bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night waking, parasomnias, sleep-disordered breathing and daytime sleepiness. The caregivers of patients were requested to complete this questionnaire by assessing the previous week. The overall score ranged between 33 and 99, and a threshold of 41 was used to determine the presence of any sleep disruption.

Cerebral Palsy Quality of Life for Children Questionnaire

We assessed the QOL of our patients by applying the CPQOL-Child questionnaire which was validated and found to be reliable in the children of our country.[16] The CPQOL-Child questionnaire has also been used as self- and proxy-administered in different ethnic groups and has been found to be valid and reliable.[17,18] The questionnaire, which was completed by the caregivers, comprises seven domains: social well-being and acceptance, participation and physical health, functioning, emotional well-being and self-esteem, the consequences of disability and pain, family health, and accessibility to services. Among these, the first five domains were also administered to children aged 9–12 years, provided that they had sufficient cognitive ability to understand the questions. Therefore, while the full questionnaire was answered by caregivers of all children aged 6–12 years, only the child-directed section (covering the first five domains) was applied to children aged 9–12 years.

Statistical methods

Statistical analyses were performed using the NCSS (Number Cruncher Statistical System) software. Descriptive statistics included mean, standard deviation, median, frequency, percentage, minimum, and maximum values. The distribution of all numerical variables was assessed using the Shapiro-Wilk test and graphical methods, and all were found to follow a normal distribution. Therefore, comparisons between two groups were conducted using the Student's t-test, and the results were presented as mean ± standard deviation. Correlations between numerical variables were assessed using Pearson correlation analysis. A p-value of <0.05 was considered statistically significant. In addition, due to the relatively small sample size, effect sizes (Cohen's d) were calculated. Cohen's d values of 0.2, 0.5, and 0.8 were considered to indicate small, medium, and large effects, respectively, while values above 0.8 were interpreted as very large effects.

Results

Demographic data

One hundred patients were admitted for our study. Nevertheless, 29 of these individuals did not attend their follow up visits due to the COVID-19 pandemic during the data collection period. Consequently, 71 patients were included in the study (42 males, 59%) with a mean age of 8.34 ± 2.18 years. While almost half of our patients (n=35, 49.3%) were premature, less than half had normal birth weight (normal birth weight: n=34,47.9%, low birth weight: n=18, 24.4%, very low birth weight: n=19, 26.8%).

The median age of the mothers at the time of delivery were 28 (min-max: 15-48) years old. Most of the mothers (n=54, 76.1%) had low level of education. While the majority had medium income (n=47, 66.2%), and almost one third of the parents had low income (n=23, 32.4%). There was only one patient whose family had a high income level (1.4%).

The relationship between CPQOL scores and demographic-neurologic findings

Clinical features, EEG, and brain MRI findings of the patients are summarized in Table I. Overall CPQOL parent-proxy and CPQOL child-proxy scores of the patients were 348.7 ± 82.1, and 331.8 ± 44.1, respectively. The CPQOL parent-proxy scores were significantly better in the high-educated mother group than in the low-educated mother group (387.1 ± 64.2 vs. 336.6 ± 83.9; p=0.026; Cohen's d=0.6) and similarly they were better in the medium-income group than the low-income group (366.1 ± 79.6 vs. 312.3 ± 76.4; p=0.009; Cohen's d=0.68). Detailed data are given in Table II. The CPQOL scores were not significantly different between the normal, low, and very low birth weight groups. However, the scores were significantly better in preterm-born patients than in those with term gestational age (374.74 ± 79.6 vs. 323.44 ± 77.45; p=0.008) (The significant different domains were as follows: "Feelings about functioning", "Participation and physical health", "Emotional well-being", "Family health"). According to the classifications of both GMF (287.07 ± 69.9 vs. 393.85 ± 57.72; p=0.001) and BFMF (273.04 ± 66.1 vs. 337.38 ± 59.68; p=0.001), the patients in the severe group had significantly poorer QOL scores compared to the mild-moderate group. Furthermore, those with epilepsy (371.8 ± 77.59 vs. 315.31 ± 78.03; p=0.002; Cohen's d=0.72) and those with intellectual disability (405.48 ± 51.68 vs. 309.55 ± 76.42; p=0.001; Cohen's d=1.4) had significantly poorer QOL scores than those without. Detailed data are given in Table III.

Comparison of the relationship between CSHQ scores and CPQOL scores

The median CSHQ score of our patients was 45 (33-69), and 78.9% (n=56) of them had sleep disorders. There was a significant negative correlation between the CSHQ and CPQOL scores of patients (r=-0.237; p=0.047) (The significant different domains were as follow: "Bedtime resistance", "Delay starting sleep", "Duration sleep", "Parasomnia", "The amount of sleep"). Detailed data are given in Table IV.

Table I. Neurological examination and laboratory findings of children with spastic cerebral palsy (N: 71).

Examination / laboratory findings		n (%)
Spasticity limb involvement	Hemiplegia	17 (23.9%)
	Diplegia	30 (42.2%)
	Quadriplegia	24 (33.8%)
GMFCS level	Mild or moderate	41 (57.7%)
	Severe	30 (42.3%)
BFMF level	Mild or moderate	47 (66.2%)
	Severe	24 (33.8%)
Intellectual disability	Yes	29 (40.8%)
	No	42 (59.2%)
Autism	Yes	60 (84.5%)
	No	11 (15.5%)
Brain MRI	PVL	28 (39.4%)
	HIE	12 (16.9%)
	Vascular	8 (11.2%)
	Ischemic infarction	6 (8.4%)
	Bleeding	2 (2.8%)
	Congenital malformation	5 (7%)
	Encephalomalacia / porencephaly	5 (7%)
	CNS infection	4 (5.6%)
	*Operated brain tumor	3 (4.2%)
	Normal	6 (8.5%)
Epilepsy	Absence of epilepsy	42 (59.1%)
	Presence of epilepsy	29 (40.8%)

BFMF: Bimanual Fine Motor Function; CNS: central nervous system; EA: electrical activity; GMFCS: Gross Motor Function Classification System; HIE: hypoxic ischemic encephalopathy; MRG: magnetic resonance imaging; PVL: periventricular leukomalacia.
*:Patients underwent brain tumor surgery after the diagnosis of cerebral palsy.

Table II. Comparison of quality of life scores of the mothers according to education and income levels.

	Education Level				Income Level			
Domain of CPQOL-Child	Low (n=54)	High (n=17)	p	Cohen's d	Low (n=23)	Middle (n=47)	p	Cohen's d
Overall	336.6±83.9	387.1±64.2	**0.026**	0.6	312.3±76.4	366.1±79.6	**0.009**	0.68
Social well-being and acceptance	66.9±23.4	80.5±13.3	**0.004**	0.6	63.2±22.3	73.6±21.5	0.064	0.58
Feelings about functioning	64.2±23.3	76.2±22	0.065	0.5	58.3±21.7	71.3±23.2	**0.027**	0.57
Participation and physical health	53.8±24.3	67.4±19.3	**0.047**	0.58	46±22.3	62.3±22.9	**0.005**	0.72
Emotional well-being	37.6±10.7	42±6.9	0.177	0.4	34.9±9.1	40.4±10	**0.012**	0.56
Access to services	49.5±14	51.4±18.5	0.647	0.12	46.7±15.6	51.5±14.8	0.214	0.31
Pain and feeling about disability	31.8±11.4	30.6±13.3	0.730	0.1	31.7±11	31.4±12.3	0.915	0.02
Family health	24.3±7.1	25.7±8.6	0.502	0.7	21.2±8.1	26.33±6.6	**0.007**	0.7

CPQOL: Cerebral palsy quality of life.

Table III. Comparison of quality of life scores based on presence of epilepsy and intellectual disability in patients with spastic cerebral palsy.

	Epilepsy				Intellectual disability			
	Yes (n=29)	No (n=42)	p	Cohen's d	Yes (n=42)	No (n=29)	p	Cohen's d
QOL Child	315.31±78.03	371.80±77.59	**0.002**	0.72	309.55±76.42	405.48±51.68	**0.001**	**1.4**
Social WB and acceptance	58.79±23	78.14±17.93	**0.001**	**0.96**	60.57±22.92	84.24±10.82	**0.001**	**1.2**
Feelings about functioning	57.79±20.92	73.61±23.09	**0.004**	0.71	56.76±21.11	82.21±17.96	**0.001**	**1.2**
Participation and PH	48.03±22.56	63.31±22.96	**0.007**	0.67	45.98±21.98	73.14±16.27	**0.001**	**1.3**
Emotional WB	34.13±9.40	41.81±9.37	**0.001**	**0.81**	34±9.74	45.45±5.82	**0.001**	**1.3**
Access to services	48.6±14.11	50.76±15.94	0.607	0.14	47.33±13.89	53.83±16.3	0.076	0.4
Pain and feeling about disability	33.82±10.08	29.92±12.76	0.175	0.33	32.14±11.84	30.62±12.01	0.598	0.12
Family health	24.20±6.67	25.02±8.07	0.493	0.1	23.14±7.14	26.93±7.55	**0.035**	0.5

CP: Cerebral palsy; PH: physical health; QOL: quality of life; WB: well-being.

Comparison of parent proxy and child proxy CPQOL results

There was a significant positive correlation between the overall scores obtained from the QOL questionnaire by patients who were able to complete the questionnaire themselves (n:18) and their mothers (r=0.942; p=0.001). This correlation was significant in all domains except the disability pain and impact. In the disability pain and impact domain, the mothers' scores were significantly higher than the children's scores (32.5 (17-50) ; 29 (8-68)).

Discussion

We utilized the CPQOL-Child questionnaire in order to evaluate the QOL for children aged 6 to 12 years who had spastic cerebral palsy. Besides, we examined the relationship between demographic, neurologic and sleep disorder variables as well as quality of life. Our findings showed that higher income levels, higher maternal education, and the lack of comorbid conditions such as epilepsy, intellectual disability, and sleep disorders had a significant positive effect on QOL. Additionally, in our subanalysis, we found that social participation played a crucial role in influencing these results.

Although education is primarily a social issue, it is crucial for mothers of children with CP to be informed about their child's condition and care in terms of rehabilitation strategies. Limitations in motor functions caused by CP require additional support from families for children with CP and this can only be achieved through family education. We found that the QOL of children of mothers with low education level was poorer than that of children of mothers with high education level. Additionally, the effect size was medium according to the differences in education level. We conclude that this result is important and should be supported by studies with a larger number of patients. Moreover, when we analyzed the QOL scale answered by mothers with low education level, we found a significant decrease in the participation and physical health sub-parameters, in which social welfare and acceptance as well as motor limitations were predominantly evaluated. With these results, we have shown that the participation of children with spastic CP in society is closely related to family education.

Table IV. Correlation of quality of life scale scores and sleep scale scores in patients with spastic cerebral palsy.

CSHQ scores		CPQOL-Child							
		QOL child	Social WB and acceptance	Functionality	Participation and PH	Emotional WB and self-esteem	Access and service	The pain and impact of disability	Family health
Total sleep score	r	-0.237	-0.016	-0.275	-0.236	-0.151	-0.162	0.133	-0.247
	p	0.047	0.896	0.020	0.047	0.209	0.176	0.269	0.038
Bedtime resistance	r	0.138	0.271	0.075	0.058	-0.006	0.100	-0.171	0.085
	p	0.251	0.022	0.536	0.629	0.957	0.405	0.155	0.480
Delay in starting to sleep	r	0.454	0.355	0.437	0.463	0.418	0.061	-0.089	0.155
	p	0.001	0.002	0.001	0.001	0.001	0.615	0.458	0.198
Duration of sleep	r	0.296	0.303	0.194	0.271	0.205	0.074	-0.029	0.179
	p	0.012	0.010	0.104	0.022	0.086	0.537	0.808	0.135
Sleep anxiety	r	-0.182	-0.069	-0.240	-0.244	-0.196	-0.086	0.119	-0.127
	p	0.129	0.566	0.044	0.041	0.101	0.477	0.323	0.290
Wake up at night	r	-0.246	-0.192	-0.179	-0.235	-0.169	-0.106	0.017	0.022
	p	0.038	0.109	0.135	0.048	0.160	0.379	0.891	0.858
Parasomnia	r	-0.604	-0.393	-0.581	-0.593	-0.570	-0.248	0.134	-0.374
	p	0.001	0.001	0.001	0.001	0.001	0.037	0.266	0.001
RD during sleep	r	-0.126	-0.102	-0.112	-0.152	-0.159	0.010	-0.129	0.024
	p	0.296	0.395	0.354	0.206	0.185	0.932	0.285	0.844
Day time sleep	r	-0.015	0.029	-0.048	-0.080	0.075	-0.016	0.227	-0.127
	p	0.904	0.807	0.693	0.505	0.532	0.893	0.056	0.291
Amount of sleep	r	0.320	0.390	0.331	0.287	0.291	0.041	-0.164	0.174
	p	0.006	0.001	0.005	0.015	0.014	0.736	0.172	0.147

CP: Cerebral palsy; CPQOL-Child: Cerebral Palsy Quality of Life Questionnaire for Children; CSHQ: Child Sleep Health Questionnaire; PH: physical health; QOL: quality of life; RD: respiratory disorder; WB: well-being.

Similarly, the QOL of the mothers with a low level of education was observed to be significantly poorer than the mothers with a higher level of education in a study conducted by Fadwa et al [19], in Sudan. However, in contrast to us, they did not perform a subanalysis based on the questionnaire.

The QOL scores in the low income group was significantly poorer than in the high income group in our study. Additionally, the effect size was medium according to the differences in income level. This finding is consistent with a study by Power et al.[20], which assessed the QOL of CP patients in low- and middle-income countries. On the contrary, our study showed that variables such as access to hospital, communication with the child's physician, and access to rehabilitation services such as physical therapy, speech therapy and occupational therapy were not affected by financial income. In our country, rehabilitation programs for these patients are provided free of charge. Additional fees may be charged when necessary. Despite having access to these health services, low-income patients still face challenges in areas such as physical and emotional well-being, self-esteem and family health.

In recent years, advancements in neonatal care have led to an increase in the survival rates of preterm and low birth weight babies. Despite this progress, there has been a corresponding rise in the likelihood of conditions such as intracranial hemorrhage, sepsis, and hypoglycemia that may negatively impact brain development. Despite this, we showed that patients with CP born preterm had a better QOL than patients with CP born at term. This may be due to the fact that our patients with CP born preterm may have shown a better clinical course than patients with CP born at term. Therefore, we suggest that QOL scores may be a more complicated outcome than assumed and can be affected by a combination of several other findings including demographic and clinical features.

The study focused on the topographic subgroup of CP patients with spastic movement disorders. Since our results may be affected by subgroup types, a more homogeneous group was selected. Our results were consistent with the expectation that patients with hemiplegia would have better QOL than other types including quadriplegia and diplegia due to their better ambulation ability. Similarly, Öcal Eriman et al.[21] also found higher QOL in patients with hemiplegia. In our study, in addition to this finding, it was found that some sub-parameters of QOL such as pain, concerns about the disease, feeling of disability, physical health and happiness of the family were not affected by type of CP.

When the motor capacities of the patients were analyzed, it was seen that those with severe GMF and BFMF levels had significantly poorer QOL, which was consistent with the existing literature.[9,19] Patients with severe motor dysfunction had significantly lower levels of functioning, physical health and participation. Similar to our data, a study by Simeonsson et al.[22] found that children with severe disabilities participated less in social activities than those with mild disabilities. On the other hand, the scores on the QOL scale regarding the impact of disability and pain in the group of patients with severe motor dysfunction were similar to those of the group with mild to moderate motor dysfunction. Interestingly, this data showed that the level of motor impairment was not directly related to the amount of pain perceived. These findings overlap with the findings of a study conducted by Badia et al.[16]

Epilepsy is known to frequently co-occur with CP. Studies show that 15 to 60% of children with CP also have epilepsy.[23] Consistent with the literature, we found that the rate of epilepsy in our patient cohort was 40.8%. Patients with CP accompanied by epilepsy had a poorer QOL compared to those without epilepsy. Both conditions affect not only individuals but also their families. In this context, a study by Terra et al.[24] evaluated the QOL of mothers of children with CP and epilepsy was found to be lower than that of mothers of CP patients only. Although we did not evaluate the mothers, QOL scores were significantly poorer in the patients with

epilepsy then in the patients without epilepsy in our study. However, we did not observe a significant difference in QOL scores between patients with and without epilepsy in the sub-dimensions of family health, access and service.

Furthermore, it is well-established that a substantial proportion of individuals with CP also have intellectual disabilities, with estimates ranging from 30 to 50%.[25] Our study revealed an even higher prevalence, as more than half of the participants displayed cognitive impairment. We found that patients with intellectual disability had significantly poorer QOL compared to those with normal intellectual functioning. Also, the effect size was very large according to the differences in intellectual functioning. When the sub-domains that cause low QOL were examined; similar to the results of a study conducted by Arnaud et al.[26], mothers of patients with intellectual disability specifically reported that their children were not sufficiently socially accepted. Blasco et al.[9] approached the patients from a neuropsychological perspective. They evaluated visual perception, executive functions, memory, psychological adjustment, and general intellectual functions of the patients. They utilized specific tests and scales, such as Raven's Color Progressive Matrices (RCPM) for general intellectual functioning, the Face Recognition Test (FRT), and the Arrows subtest of the NEPSY-II for visual perception. As a result, they demonstrated the significant impact of neuropsychological factors, including executive functions, on the QOL of children with CP.[9]

First, we hypothesized that children with CP are more likely to have sleep disturbances than their healthy peers due to motor dysfunction limiting their ability to move and change position in bed which can cause more awakenings, pain and airway obstruction during sleep. In line with our predictions, it has been reported that sleep disorders are four times more common in children with CP than in children with normal development.[27-30] Previous studies have also shown a high prevalence of parasomnia in patients with behavioral problems and intellectual disabilities.[31,32] Although there was no relationship between intelligence level and sleep disorders, sleep disturbances were significantly more common in children with CP in our study. Furthermore, there was a significant positive correlation between the sleep disturbance frequency and both of the severity of motor functions and QOL scores. Therefore, our study, which evaluated sleep disturbances, QOL and motor function levels together, may provide valuable insights for the literature. The points we highlight may be particularly helpful for clinicians working with children with CP in assessing the overall well-being of their patients.

This study also aimed to compare parents' and children's perspectives on QOL, as emphasized by Swift et al.[33] We found that all the subdomains but "the pain and impact of disability" were highly consistent between the responses of children and their caregivers. This finding points out that although mothers are quite reliable sources for the data obtained regarding QOL, pain assessment is highly dependent upon the patient itself. Thus, we suggest that if the patient is unable to complete the questionnaire and we have to ask the mothers, we must be aware of possible exaggerated responses regarding the pain of the patients.

There are several noteworthy limitations of our study. The main limitation was the very low frequency of child responses, with lower than one fifth of the patients able to answer the questionnaire, therefore our data was mostly based on the mother's responses. Another limitation was the highly heterogeneous cohort which varied greatly in terms of topography and severity of the patients' neuromotor impairment.

In conclusion, the optimal care for a child with spastic CP should take into account family and environmental factors. Improving financial support for families, increasing mothers' education levels, providing early and effective physiotherapy for walking, developing gross and fine motor skills, implementing

personalized intellectual stimulation strategies from an early age, and promptly addressing sleep disorders and epilepsy can significantly improve a patient's QOL. Relying solely on parents' perspectives may ignore the valuable information that children can provide and vice versa. Therefore, asking both the children and their caregivers might offer a reliable method to evaluate the QOL of these patients.

Acknowledgements

The authors declare special thanks to Songul Uysal, who validated the scale we used Aysun Ayaz Sari, the pedagogue of their tertiary center, for performing the Denver test on the patients.

Ethical approval

The study was approved by Institutional Review Board (08/07/20-29430533-604.01-01-86126) of Istanbul University-Cerrahpasa, Cerrahpasa Medical School. The study complied with the recommendations of the Declaration of Helsinki for human biomedical research. The caregivers provided informed consent on behalf of all the participants.

Author contribution

The authors confirm contribution to the paper as follows: Study conception and design: LK, SG, SS; data collection: LK; analysis and interpretation of results: LK, SS; draft manuscript preparation: LK. All authors reviewed the results and approved the final version of the article.

Source of funding

The authors declare the study received no funding.

Conflict of interest

The authors declare that there is no conflict of interest.

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