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Factors Affecting The Quality of Life of Children with Cerebral Palsy: A Single-Center Study

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Abstract

Objective: Quality of life (QoL) encompasses an individual's well-being across physical, psychological, and social dimensions and reflects how satisfying, healthy, and meaningful their life feels. This study aims to identify the variables that impact QoL in children with cerebral palsy (CP) and to determine which of these variables has the greatest impact.

Materials and Methods: This study included 100 children with CP, aged 3–18 years, who were regularly followed up at a pediatric neurology outpatient clinic. Data were collected on age, sex, presence of epilepsy, intellectual disability, caregiver's perceived economic status, and caregiver's education level. The children were assessed using the Gross Motor Function Classification System (GMFCS), the Face, Legs, Activity, Cry, Consolability (FLACC) pain scale, the Epworth Sleepiness Scale (ESS), and the Pediatric Quality of Life Inventory (PedsQL). Multiple regression analysis was performed to examine the effects of these variables on QoL.

Results: In children with CP, QoL was positively associated with increasing age and the caregiver's perceived economic status. Conversely, higher GMFCS levels, higher FLACC and ESS scores, and the presence of epilepsy were associated with lower QoL. Among these variables, the GMFCS had the most significant negative impact on QoL. Sex, caregiver's education level, and intellectual disability did not have any effect on QoL.

Conclusion: In children with cerebral palsy, pain reduction, control or absence of epilepsy, decreased sleepiness, and particularly improvements in gross motor function levels and perceived economic status can significantly contribute to enhancing the quality of life.

Keywords Cerebral palsy · Gross Motor Function · Pain · Quality of Life · Sleep

Author Note This study was Dr Bener's pediatric residency research thesis. We declare that this manuscript is original, has not been published in any journals and is not currently being considered for publication else where. It was presented at the 18th Ulusal Uludağ Pediatri Kış Kongresi under the name "Serebral Palsili Çocukların Ağrı Durumları"

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INTRODUCTION

Cerebral palsy (CP) is a non-progressive neurodevelopmental disorder affecting movement, posture, and balance due to brain damage occurring in the fetal or perinatal period (1,2). It is the most common childhood physical disability, with a prevalence of 2–2.5 per 1000 births (3). Epilepsy, secondary musculoskeletal complications, and cognitive or sensory deficits often accompany motor impairments in children with CP (2).

Quality of life (QoL) reflects the overall impact of disease, environment, and personal factors across physical, emotional, mental, and social domains (4-6). Factors such as parental characteristics, co-morbidities and severity of cognitive impairment can influence the outcome and thus the QoL of individuals with CP (7). Identifying QoL determinants is essential for optimizing treatment strategies, as modifiable factors such as pain and motor function can be improved through interventions (8), while non-modifiable factors provide prognostic insights for clinicians.

Previous studies indicate that QoL is affected by pain, sleep disturbances, ambulatory status, epilepsy, comorbidities, and socioeconomic factors (3,4,7,9-12). Sleep, pain, and epilepsy are interrelated factors affecting QoL. Epilepsy, common in CP, disrupts sleep physiology and increases the risk of sleep disorders, while antiepileptic drugs may cause daytime sleepiness (13). Additionally, pain contributes to sleep disturbances, further reducing QoL (4). Understanding the relative impact of these factors is essential for targeted interventions.

Previous studies have mostly evaluated QoL factors separately, without considering their potential interactions. However, examining the combined effects of these factors may uncover new insights. Despite various factors being studied, research identifying the most influential determinants of QoL remains limited, highlighting the need for a more comprehensive understanding to guide targeted interventions.

This study aims to assess the impact of age, sex, gross motor function level, perceived economic status of the primary caregiver, education level of the primary caregiver, presence of epilepsy, presence of intellectual disability, pain, and daytime sleepiness on the QoL in children with CP. Additionally, it seeks to determine which of these factors has the greatest impact on QoL outcomes.

MATERIAL AND METHODS

This single-center, hospital-based, cross-sectional observational study was approved by the Clinical Research Ethics Committee of the Health Sciences University (decision no. 2012-KAEK-15/1957, 11 September 2019). Informed consent was obtained from all the children's parents and adolescents.

Participants

This study included individuals with CP between the ages of 3 and 18 years who were admitted to the Dr. Sami Ulus Maternity, Children's Health and Diseases Training and Research Hospital, Pediatric Neurology Outpatient Clinic between September 2019 and November 2019. Children with other major conditions, such as neurometabolic or neurodegenerative diseases, chromosomal anomalies, renal failure, and liver failure, were excluded from the study. In addition, those who had newly diagnosed epilepsy, had uncontrollable seizures, and had undergone epilepsy surgery were not included.

In a meta-analysis study on CP conducted by Makriz et al. (6), it was reported that the variables affecting the QoL in these individuals had a moderate to large effect size, ranging from 0.42 to 1.58. Based on this, a moderate effect size was assumed for the power analysis, which was then conducted accordingly. As a result of the power analysis, the minimum required sample size was determined to be 55 (power analysis conditions: moderate effect size, two-tailed hypothesis, $\alpha = .05$, $\beta = .80$, and number of predictors = 8). The power analysis was conducted using the G*Power software (version 3.1.9.7). After data collection, a post hoc power analysis was performed, and β was found to be .97 for n = 100.

Procedure

All data regarding the children were collected during their routine outpatient clinic visits. The children's clinical and demographic characteristics, as well as medical history (e.g., age, epilepsy), were obtained from patient files, while family-related information (e.g., primary caregiver's perceived economic status, education level of the caregiver) was gathered through direct questions to the primary caregivers. The intellectual disability status of the child was determined by reviewing the medical records, where it was noted that the diagnosis of intellectual disability was made following prior medical assessments. To assess the family's perception of their economic status, caregivers were asked whether their income met community standards. They responded to the following question: How do you perceive your family's economic situation compared to society in general?

The Pediatric Quality of Life Inventory (PedsQL), which assesses the QoL of children with CP, and the Epworth Sleepiness Scale (ESS), which evaluates daytime sleepiness, were completed by the parents. The researchers assessed the

FLACC (Face, Legs, Activity, Cry, Consolability) pain scale to evaluate the pain experienced by the children and completed the Gross Motor Function Classification System (GMFCS) to determine their gross motor function levels. All scales were administered in their original form but in the language of the participants.

Quality of life

The Pediatric Quality of Life Inventory (PedsQL), developed by Varni et al. (1999, 2001) (14,15), evaluates children's QoL across four age groups: 2–4, 5–7, 8–12, and 13–18 years. This scale is valid and reliable for children with CP (14-18). For the 2–4 age group, only the parent proxy form is available, whereas both child self-report and parent proxy forms exist for the 5–18 age groups. The 5–7 age group uniquely used a three-point response scale, while all other versions used a five-point scale. The 2–4 age group version consists of 21 items (8 physical, 5 emotional, 5 social, and 3 school-related questions), while all other versions contain 23 items, with 5 school-related questions. The total score is derived from all questionnaire items, while the subscale scores assess physical health and psychosocial health (emotional, social, and school functioning). Responses were scored as: "Never" = 100, "Rarely" = 75, "Sometimes" = 50, "Often" = 25, "Almost always" = 0. The final score is calculated by summing the item scores and dividing by the number of completed items, with higher scores indicating better QoL (14-18).

In this study, the Turkish version of PedsQL™ 4.0 was used to assess QoL.

Pain measurement

The Face, Legs, Activity, Cry, Consolability (FLACC) scale, developed by Merkel et al. in 1997 (19,20), assesses pain in non-verbal children and is widely accepted for use in individuals with cognitive impairment up to age 18 (21,22). It evaluates five behavioral categories -facial expression, leg movement, activity level, crying, and consolability—each scored from 0 to 2, with a total score of 0 to 10 indicating pain severity. Higher FLACC scores correspond to greater pain intensity (20).

In 2008, Voepel-Lewis et al. evaluated the FLACC scale as a pain assessment tool for children with cognitive impairment (23). In 2010, they confirmed its validity and reliability across diverse patient groups, indicating strong internal consistency (24).

Evaluation of daytime sleepiness

The Epworth Sleepiness Scale (ESS) is a validated, reliable tool designed to assess daytime sleepiness (25-28). Individuals rated their likelihood of falling asleep in eight common daily situations over the past month using a four-point scale: 0 (no chance), 1 (slight), 2 (moderate), and 3 (high chance), with total scores ranging from 0 to 24. Higher scores indicated greater daytime sleepiness (25-27). The cut-off value for the scale was taken as 10, which means that results over 10 indicate daytime sleepiness with high sensitivity and specificity (26).

Evaluation of the gross motor function

The Gross Motor Function Classification System (GMFCS) was developed by Palisano et al. in 1997 to classify gross motor function levels in children with CP aged 2–12 years (29). However, in 2007, the system was revised to include children and adolescents aged 12–18 years, and its validity and reliability were demonstrated by Palisano et al. in 2008 (2,30). The GMFCS categorizes gross motor function into five levels, focusing on sitting, walking, and mobility:

Level I: Walks independently but has limitations in advanced gross motor skills.

Level II: Walks without assistive devices but struggles with community mobility.

Level III: Walks with handheld mobility aids; limited community mobility.

Level IV: Has severely limited self-mobility; may use a powered wheelchair but primarily relies on assistance.

Level V: Mobility is significantly restricted despite assistive technologies; requires transportation in a manual wheelchair (30).

Statistical analyses

Statistical analyses were performed using the Statistical Package for the Social Sciences version 25.0 (IBM Corp., Armonk, NY, USA) software. The suitability of the numerical variables for normal distribution was determined using visual (histogram and probability graphs) and analytical methods (Kolmogorov–Smirnov). Descriptive statistics included frequency and percentage for categorical variables and mean, standard deviation, and range for continuous variables. The Pearson correlation coefficient examined variable relationships. The effect of the independent variables (age, sex, GMFCS, presence of intellectual disability, FLACC, ESS, the caregiver's perceived economic status, education status of the caregiver) on the dependent variable (QoL) was determined using multiple linear regression analysis (Enter method). Assumptions were met, with no multicollinearity (VIF: 1.10–1.93; Tolerance: 0.52–0.91; Condition Index: 18.88) or outliers (z-scores: -1.90 to 1.74). ANOVA tested for age-related differences, while independent samples t-tests compared QoL by sex and epilepsy status.

The regression assumptions of normality, linearity, and homoscedasticity were satisfied. The statistical significance level was set as p< .05.

RESULTS

A total of 100 children with CP (62 males, 38 females, mean age: 9 ± 4 years) were included in the study. The clinical and demographic characteristics of the children are presented in Table 1.

In the study group, children aged 13-18 years had the highest GMFCS and FLACC scores and the lowest PedsQL-Total scores (Table 2). While there was no difference between males and femaless in terms of PedsQL scores, the total and some subscores decreased in the presence of epilepsy or intellectual disability (Table 3).

The PedsQL demonstrated statistically significant associations with GMFCS, FLACC and ESS in the study (p < .05) (Table 4).

It was observed that age, caregiver's perceived economic status, presence of epilepsy, GMFCS, FLACC, and ESS scores had a statistically significant impact on PedsQL-Total Scores. The presence of intellectual disability, sex, and the caregiver's education level were not found to be statistically significant (Table 5).

Higher perceived economic status (β = 0.17, p = .012) and older age (β = 0.14, p = .043) were associated with improved PedsQL-Total Scores, whereas higher GMFCS (β = −0.36, p < .001), ESS (β = −0.31, p < .001), FLACC (β = −0.27, p < .001) scores and presence of epilepsy (β = −0.23, p = .001) were linked to a decline in PedsQL scores. PedsQL scores increased with both children's age and the caregiver's perceived economic status. Additionally, the caregiver's perceived economic status was a stronger positive predictor of PedsQL scores than age (β = 0.14, p = .043). Among all predictors, caregiver's perceived economic status was the strongest positive predictor (β = 0.17, p = .012), while GMFCS was the strongest negative predictor (β = −0.36, p < .001) (Table 5).

DISCUSSION

In this study examining the factors affecting the quality of life (QoL) of children with cerebral palsy (CP), it was found that increasing age and the caregiver's perceived economic status significantly positively affected the QoL, while higher GMFCS levels, the presence of epilepsy, pain, and daytime sleepiness had a negative impact. Among these factors, the GMFCS level had the most significant negative effect, while the caregiver's economic status had the most significant positive effect.

Table 1. Distribution of children's demographics and some characteristics

Sociodemographic Variable	Frequency	Percentage (%)
Sex		
Female	38	38.0
Male	62	62.0
Age		
2-4 years	17	17.0
5-7 years	27	27.0
8-12 years	29	29.0
13-18 years	27	27.0
GMFCS		
Level 1	18	18.0
Level 2	34	34.0
Level 3	21	21.0
Level 4	7	7.0
Level 5	20	20.0
Type of CP		
Hemiparetic	42	42.0
Diparetic	25	25.0
Quadriparetic	33	33.0
Presence of Epilepsy		
Present	59	59.0
Absent	41	41.0
Presence of an Intellectual Disability		
Present	46	46.0
Absent	54	54.0
Primary Caregiver's Perceived Economic Status		
Low	20	20.0
Below Average	42	42.0
Average	23	23.0
Upper/Above Average	15	15.0
Education Level of the Primary Caregiver		
Primary School and Below	53	53.0
Secondary School–High School	31	31.0
Higher Education	16	16.0
	Min-max	**Mean±Std**
ESS	0-16	5.44 ± 4.69
FLACC	0-10	1.28 ± 21.52
PedsQL		
PedsQL-Physical	0-100	50.62 ± 28.96
PedsQL-Psychosocial	22.50-98.33	66.19 ± 18.62
PedsQL-Emotional	30-100	73.95 ± 18.27
PedsQL-Social	0-100	58.70 ± 27.83
PedsQL-School	20-100	77.09 ± 19.16
PedsQL-Total Score	19.44-97.82	60.28 ± 21.52

CP, cerebral palsy; ESS, Epworth Sleepiness Scale; FLACC, Face, Legs, Activity, Cry, and Consolability Pain Scale; GMFCS, Gross Motor Function Classification System; Max, maximum; Min, minimum; PedsQL, Pediatric Quality of Life Inventory; Std deviation, standard deviation

Table 2. Comparison of variables by age group

Variables	Children's Age	Min	Max	Mean	Std	p-value	Difference
	2-4 ages (1)	1	5	3.12	1.17		
	5-7 ages (2)	1	5	2.33	1.07		
	8-12 ages (3)	1	5	2.17	1.31		
GMFCS	13-18 ages (4)	1	5	3.63	1.39	**<.001***	4 > 2;3
	2-4 ages (1)	0	5	0.65	1.66		
	5-7 ages (2)	0	7	0.70	1.66		
	8-12 ages (3)	0	7	0.66	1.59		
FLACC	13-18 ages (4)	0	10	2.93	3.63	**.001***	4 > 1;2;3
	2-4 ages (1)	0	11	4.35	3.89		
	5-7 ages (2)	0	16	4.93	4.37		
	8-12 ages (3)	0	16	6.00	5.10		
ESS	13-18 ages (4)	0	16	6.04	5.06	.561	–
	2-4 ages (1)	23.61	93.06	57.43	18.04		
	5-7 ages (2)	34.72	93.48	64.96	18.06		
	8-12 ages (3)	29.17	97.83	67.73	22.36		
PedsQL-Total Score	13-18 ages (4)	19.44	96.74	49.42	22.05	**.006***	2;3 > 4

*ANOVA test; p-value in bold type denotes a significant difference *p< .05.
ESS, Epworth Sleepiness Scale; FLACC, Face, Legs, Activity, Cry, and Consolability Pain Scale; GMFCS, Gross Motor Function Classification System; Max, maximum; Min, minimum; PedsQL, Pediatric Quality of Life Inventory; Std, standard deviation

Table 3. Comparison of PedsQL scores by sex, epilepsy, and intellectual disability

Variable	Female (Mean±Std)	Male (Mean±Std)	p-value (Gender)	No Epilepsy (Mean±Std)	Epilepsy (Mean±Std)	p-value (Epilepsy)	No intellectual disability (Mean±Std)	Intellectual disability (Mean±Std)	p-value (Disability)
PedsQL-Physical	48.60±28.09	51.86±29.64	.587	58.90±28.33	38.72±25.82	< .001	65.86±25.37	32.74±21.96	< .001
PedsQL-Psychosocial	63.75±18.34	67.68±18.80	.309	71.68±17.26	58.29±17.85	< .001	74.80±15.77	56.09±16.66	< .001
PedsQL-Emotional	70.53±17.62	76.05±18.49	.143	76.27±17.53	70.61±19.01	.128	76.76±16.26	70.65±20.07	.102
PedsQL-Social	57.11±27.00	59.68±28.51	.656	67.63±25.06	45.85±26.85	< .001	73.61±19.46	41.20±26.06	< .001
PedsQL-School	67.41±23.25	75.28±19.85	.131	77.90±21.16	63.62±19.36	.005	80.37±17.20	57.69±20.84	< .001
PedsQL-Total Score	58.18±21.04	61.58±21.88	.447	67.37±20.23	50.09±19.30	< .001	72.46±17.31	45.99±16.72	< .001

*t-test; p-value in boldtypedenotes a significantdifference *p< .05.
Max, maximum; Min, minimum; PedsQL, Pediatric Quality of Life Inventory; Std, standard deviationn

Table 4. Correlations of variables (n = 100)

Variables	Age	GMFM	FLACC	ESS	PedsQL-Total Score
Age	–				
GMFCS	.26	–			
FLACC	.18	.12	–		
ESS	.05	.16	.28	–	
PedsQL-Total Score	.06	**-.40***	**-.41***	**-.46***	–

*Pearson's correlation analysis; p-value in bold type denotes a significant difference *p< .05.
ESS, Epworth Sleepiness Scale; FLACC, Face, Legs, Activity, Cry, and Consolability Pain Scale; GMFCS, Gross Motor Function Classification System; Max, maximum; Min, minimum; PedsQL, Pediatric Quality of Life Inventory; Std deviation, standard deviation

Table 5. Factors affecting the quality of life (PedsQL-Total Score) of children with cerebral palsy

Predictor variables	R	R^2	ΔR^2	p (ΔR^2)	B	95% CI		β	t	*p*	R
						Lower	Upper				
Intercept	.84	.71	.71	<.001	82.21	67.24	97.18	–	10.91	<.001	–
Sex					−1.24	−6.45	3.97	-.03	−0.47	.638	.08
Age					**0.67**	**0.02**	**1.32**	**.14**	**2.06**	**.042**	-.20
Caregiver's perceived economic status					**3.78**	**0.89**	**6.66**	**.17**	**2.60**	**.011**	.33
Education level of the caregiver					−0.91	−3.52	1.70	-.04	−0.69	.492	.16
Presence of epilepsy					**-9.95**	**-15.62**	**-4.27**	**-.23**	**-3.48**	**.001**	-.40
Presence of an intellectual disability					−5.37	−12.10	1.36	-.13	−1.59	.116	-.62
GMFCS					**-5.60**	**-7.85**	**-3.35**	**-.36**	**-4.94**	**<.001**	-.62
FLACC					**-2.34**	**-3.43**	**-1.26**	**-.27**	**-4.29**	**<.001**	-.50
ESS					**-1.40**	**-1.98**	**-0.83**	**-.31**	**-4.84**	**<.001**	-.54

Multiple regression analysis (Enter method); p-value in bold type denotes a significant difference p< .05.
ESS, Epworth Sleepiness Scale; FLACC, Face, Legs, Activity, Cry, and Consolability Pain Scale; GMFCS, Gross Motor Function Classification System; PedsQL, Pediatric Quality of Life Inventory

Previous studies have shown mixed results regarding the effect of age on QoL. Some found that increasing age negatively impacted QoL (5,10,11), while others found no effect (31,32). In contrast, our study found that QoL increased with age. This may be because, as children grow, they gain experience in managing CP and its associated challenges, which may reduce stress and improve QoL over time.

In this study, interestingly, when age was treated as a continuous variable, PedsQL-Parent scores increased, while a categorical analysis showed the opposite trend. This discrepancy may be due to the relative effects of other influencing factors, leading to different outcomes depending on the statistical approach used. Additionally, since one analysis treats age as a continuous variable while the other categorizes it, the categorical approach may introduce misleading results, potentially affecting the interpretation of age-related QoL differences. Another reason for the discrepancy in the literature regarding age could be the categorization of age groups in the QoL assessment forms, with the effects being evaluated within these age groups. This possible statistical approach difference may contribute to variations in the findings across studies.

Most (4,9,10,12,33), but not all (11), studies have found that motor impairment is associated with lower QoL. Although it has been found to be associated with QoL, studies generally do not compare the impact of this factor with other factors to determine which one is more important in determining QoL. Our study found that the GMFCS level had the greatest negative impact on QoL. The severity of motor dysfunction and the likelihood of comorbidities increased with higher GMFCS levels, which may explain the significant negative effect on QoL. Therefore, the results suggest that GMFCS has the greatest negative effect on QoL.

Sleep problems are prevalent in 13%–85% of children with neurodevelopmental disorders, including CP, and are associated with reduced QoL (4,34). Epilepsy, which affects 30%–50% of children with CP, also negatively impacts QoL (9,35). Sleep disorders, intensified by epilepsy and antiepileptic drugs, further reduce QoL (4,13). Our study found that both epilepsy and daytime sleepiness negatively impacted QoL. Epilepsy may adversely affect QoL either directly or indirectly, due to reasons such as sleep disorders.

The presence of pain is an important factor affecting the QoL of children with CP and their families. In addition, pain is also an important factor in the child's participation in recreational activities, school, and community life (1,4,11). It has been reported that objective evaluation is difficult because it may be affected by the developmental conditions, pain perception, and responses of children, such as age, cognitive ability, and self-expression ability (36,37). Therefore, FLACC was used in the pain assessment, and our results showed that QoL decreased with increasing pain intensity, consistent with the results of previous studies (1,4,11).

Although some studies found weak or no associations between socioeconomic status and QoL in children with CP (33,38), Sharawat et al. found an association between lower socioeconomic status and reduced QoL (9). Our study found a positive correlation between perceived economic status and QoL. Data were obtained by asking families for their own perceptions of their economic status. Therefore, their thoughts about their economic situation may have guided their thoughts about the QoL life of their children. Families

may think that as their economic situation improves, they can provide more resources and support, and thus the QoL of their children will be better. For this reason, the economic situation is seen as a factor affecting the QoL.

Although approximately half of the individuals with CP have intellectual disabilities, the number of studies on its effect on the QoL is limited (39). Maestro-Gonzalez et al. found that the presence of intellectual disability in adults with CP decreased their QoL (3). However, in our study, intellectual disability did not affect the QoL. It was thought that this situation may be due to the distribution of the physical effect levels of children with intellectual disability in this study or to the educational and socioeconomic characteristics of the families.

Few studies have examined the relationship between caregiver's education level and the QoL of children with CP. Singer et al. found that higher education levels in caregivers led to increased involvement but also higher stress and anxiety (40). However, similar to Üneri et al., we found no effect of caregiver education on QoL in our study, where 53% of caregivers had completed primary school or less (31). Other factors, such as family acceptance and awareness of the disease, may influence this outcome.

This study has some limitations. Because this study was designed as a cross-sectional, single-center study to assess the QoL of children with CP, no control group was included. Temporal variations or individual differences may also influence the results. Furthermore, the generalizability of our results may be limited due to the single-center design and the specific socio-demographic characteristics of the study population. Therefore, multicenter studies with larger sample sizes and diverse socio-cultural backgrounds are needed to validate and expand upon our findings.

CONCLUSION

Improvements in factors affecting the QoL of individuals with CP, including pain, daytime sleepiness, epilepsy, the caregiver's perceived economic status, and particularly GMFCS level, may significantly contribute to enhancing their QoL. Among these, the caregiver's perceived economic status was the strongest positive predictor, while the GMFCS level was the strongest negative factor.

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Ethics Committee Approval: This study was approved by the ethics committee of Clinical Research Ethics Committee of the Health Sciences University (decision no. 2012-KAEK-15/1957, 11 September 2019).

Informed Consent: Written consent was obtained from the participants.

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