Quality of Life among Children with Cerebral Palsy in the Kingdom of Saudi Arabia and Various Factors Influencing It: A Cross-sectional Study

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ABSTRACT

Many neurological disorders cause disabilities in children, and cerebral palsy (CP) is one of the most common neurodevelopmental disorders. Children with CP experience reduced quality of life (QOL). CP is the most prevalent cause of disability in Saudi Arabia. This study aims to establish quantitative evidence related to QOL and the factors influencing it among children with CP. We recruited 132 participants between 2 and 18 years of age diagnosed with CP from several hospitals and rehabilitation centers. Participants were classified according to age based on the Pediatric QOL Inventory CP Module (PedsQL 3.0 CPM), which was completed by parental proxies. The Gross Motor Functional Classification System—Expanded and Revised (GMFCS-E&R) divided participants based on their functional level. Of the 132 participants, 79 were male and 53 were female. We observed reduced mean score of QOL in all PedsQL 3.0 CPM dimensions. Parents reported the lowest QOL for movement and balance activities and the highest QOL for eating activities. There was a significant negative moderate correlation between QOL and GMFCS-E&R scores ($r_s = -0.56$, $P = 0.01$) and a significant moderate positive correlation between QOL and schooling ($r_s = 0.4$, $P < 0.03$) and socioeconomic status of the family ($r_s = 0.42$, $P < 0.04$). The parents of children with CP reported poor QOL for the children. Decreased functional levels were associated with reduced QOL, whereas schooling positively impacted QOL. More frequent rehabilitation services may be required to educate and encourage positive parental involvement during rehabilitation, further enhancing QOL among children with CP.

KEYWORDS

cerebral palsy, quality of life, children, adolescents, disability, physical health, mental health, socioeconomic status, PedsQL 3.0 CPM

INTRODUCTION

Broader considerations of quality of life (QOL) supersede the concepts of mortality and morbidity in health (Pal, 1996). QOL is an overall assessment of well-being across various domains, such as physical, psychological, social, economic, and spiritual dimensions (Mihai et al., 2018). According to the World Health Organization, QOL is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (Majumdar and Jain, 2020; Asiri et al., 2023).

In the past two decades, pediatric rehabilitation has evolved from a medical model to an impairment-based treatment model in which the focus is on changing children's body structures and functions. However, now the focus is shifting from the impairment-based model to contextual factors affecting children's QOL (Ólafsdóttir et al., 2019). QOL can be enhanced by focusing on improvements across the International Classification of Functioning, Disability, and Health (ICF) domains (Williams et al., 2023).

The ICF model integrates body structure, function, activities, and participation with personal and environmental factors. Each ICF domain is essential to daily living, and all domains are interconnected (Williams et al., 2023). Therefore, in children with disabilities, dynamic interactions between impairments and functional limitations, as well as attitudinal and environmental barriers, impact their active participation in society and, therefore, their QOL (Ólafsdóttir et al., 2019).

Childhood disability occurs due to intrinsic biological and acquired conditions, such as cerebral palsy (CP), traumatic brain injury, spinal cord injury, and spina bifida, which cause impairments that lead to disability and inadequate participation in daily activities (Ansari and Akhdar, 1998; Law et al., 2014). CP is the cause of physical disability in every 2-2.5 per 1000 live births globally (Das et al., 2017; Mohamed Madi et al., 2019). Data on CP prevalence in many Middle Eastern countries are limited; however, studies in Egypt and the Sultanate of Oman have reported that this prevalence ranges from 0.7 to 4.07 per 1000 live births (Mushta et al., 2019). In 2014, the incidence of CP in Saudi Arabia was 2.5 per 1000 live births, and >200,000 new cases were reported yearly (Aman et al., 2022). CP is a neurological disorder that affects posture and movement (Soliman et al., 2019; Tedla et al., 2019; Dasoju et al., 2021).

CP is not progressive; however, it causes impairments in muscle tone, body movement, muscle coordination, and posture, which result in disability. Furthermore, attitudinal and environmental barriers impact efficient societal participation, thereby reducing QOL among children with CP (Mushta et al., 2019). Many studies have focused on assessing the QOL of children (Parisi et al., 2016; Mohamed Madi et al., 2019) and young adults with CP. Only one study has been conducted in Saudi Arabia, which assessed the relationship between the QOL of children with CP and parental mental status (Soliman et al., 2019). This study was conducted in different regions of the country and mainly focused on the relationship between QOL and maternal psychological status rather than QOL itself and the factors influencing it.

Many factors impact the QOL of children with CP, including age, gender, disease severity, comorbidity, and complications. Family-related factors that impact QOL include socioeconomic status, relationships, support, coping mechanisms, parenting style, and disease knowledge. The convenience of management, rehabilitation services, and other environmental factors can also affect the QOL of children with CP (Mushta et al., 2019). More studies are needed to determine QOL and the factors impacting it among children with CP in Saudi Arabia. Therefore, this cross-sectional study focuses on assessing the QOL and factors impacting it among children with CP in Saudi Arabia.

METHODOLOGY

This study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the ethical committee of King Khalid University, which provided ethical clearance for this cross-sectional study (approval number ECM#2023-612). The required sample size was calculated using the https://clincalc.com/Stats/SampleSize.aspx website. The mean and standard deviation (SD) from Thurston et al., 2010 study were used to calculate the sample size, with power β set at 80% and α at 0.05. The required sample size, including a 10% dropout rate, was determined to be 132. This study was conducted from March 2022 to March 2023 at King Khalid University, Abha, Saudi Arabia.

The investigators approached various hospitals and rehabilitation centers affiliated with the Ministry of Health with the approval of the ethical committee. After obtaining permission from these centers and hospitals to conduct convenience sampling, we recruited volunteer participants for data collection. To be included, participants were to be between 2 to 18 years of age and diagnosed with CP. Furthermore, we included the participants attending the centers with primary caregivers. We excluded participants suffering from associated conditions not due to CP, such as those due to trauma like accidents and falls. Children unwilling to participate or who had undergone surgery within the past 6 months were also excluded. The children who were able to provide consent filled out a consent form, and the parents of all participants also provided written consent.

We collected demographic data, such as age, gender, and schooling details of the children from the parents. The following details of the caregivers were also obtained: caregivers' education, age of the caregiver, body mass index (BMI), and socioeconomic status of the family. The medical records from the hospitals and rehabilitation centers were assessed to rule out the presence of any exclusion criteria. Participants' functional mobility levels were assessed using the Gross Motor Functional Classification System—Expanded and Revised (GMFCS-E&R). Parents filled out the Pediatric QOL Inventory CP Module (PedsQL 3.0 CPM) as proxies (Michalska et al., 2018). We retrieved the full PedsQL 3.0 CPM forms after obtaining written permission from the original authors and the Mapi Research Trust. Four PedsQL 3.0 CPM forms were used: the parent proxy report for toddlers (2-4 years), the parent proxy report for young children (5-7 years), the parent proxy report for children (8-12 years), and the parent proxy report for teens (13-18 years). The reports were either filled out using a paper-based method or an online Google Form. For the paper-based method, study-blind therapists working in the centers collected the forms from the parental proxies. Therapists were able to answer questions during the report completion process. All information collected was stored confidentially, and participants were allowed to withdraw their details at any time without affecting their rehabilitation care. The collected information was used for data analysis.

Details of the outcome measure

The PedsQL 3.0 CPM consists of 35 items that assess parents' perceptions of their children's health-related QOL in the past month across seven dimensions: daily activities (9 items), school activities (4 items), movement and balance (5 items), pain and hurt (4 items), fatigue (4 items), eating activities (5 items), and speech and communication (4 items). The toddler report does not contain the school activities or speech and communication dimensions, and the daily activities and eating activities dimensions were altered to include fewer items as not all items were applicable to toddlers. A 5-point response scale was used for both self-reports and parent proxy reports, where 0 indicated never a problem, 1 indicated almost never a problem, 2 indicated sometimes a problem, 3 indicated often a problem, and 4 indicated almost always a problem. For children aged 5-7 years who completed the self-report, the response scale was simplified to a 3-point scale, where

0 indicated not at all a problem, 2 indicated sometimes a problem, and 4 indicated often a problem. Children choose between happy and sad faces for each response.

For the scoring procedure, items were scored in reverse form and linearly transformed to a 0-100 scale, where 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. Therefore, a higher score indicated better health-related QOL. When calculating individual dimension scores, if over 50% of items had not been completed, the scale scores were not computed. The mean scores for each dimension were calculated as the total number of items divided by the number of items answered. This instrument demonstrated construct validity and internal consistency reliability (Varni et al., 2006).

Data analysis

We analyzed the data using SPSS® Statistics version 28 (IBM®, USA). The demographic characteristics were analyzed using descriptive statistics and frequencies, including the number of subjects in each category, average values, SDs, and minimum and maximum values. Correlations between QOL scores, mobility, age of the child, schooling, age of the caregiver, caregiver's education, BMI of the caregiver, and socioeconomic status were assessed using Spearman's correlation coefficient rho (r_s) values. Rho values were interpreted based on the user guide to correlation coefficients developed by Akoglu (2018) As per these guidelines, rho values of −0.3 to +0.3 were considered indicative of weak correlations, values from −0.4 to −0.6 or +0.4 to +0.6 were considered indicative of moderate correlations, and those from −0.7 to −0.9 or +0.7 to +0.9 were considered indicative of strong correlations.

RESULTS

This cross-sectional study aims to assess the QOL among children with CP aged 2-18 years. Of the 132 participants, 79 were male and 53 were female. We divided the participants into four age groups based on the PedsQL 3.0 CPM assessment: ages 2-4, 5-7, 8-13, and 14-18 years. The number of participants in each age group is presented in Table 1, as is the number of participants in each functional level of the GMFCS-E&R. The average age of the participants was 11.33 ± 7.7 years. The number of participants who attended a normal school, a special school, or did not attend any school is shown in Table 1. Mothers were the primary carers of the participants, and the primary carer distribution is also shown in Table 1. Table 2 demonstrates the details of caregivers.

The QOL scores, as measured by the PedsQL 3.0 CPM assessment, were averaged for 100, with values presented as mean, SD, and minimum and maximum values. The values for each age group across each questionnaire domain are presented in Table 3. The lowest QOL values were observed in the movement and balance domain for the 2- to 4-year-old participants, whereas the highest values were observed in the eating activities domain for 5- to 7-year-old participants.

Table 4 shows the correlations between PedsQL 3.0 CPM scores and GMFCS-E&R scores, age of the child, schooling parameters, age of the caregiver, BMI of the caregiver, caregiver's education, and socioeconomic status of the family that were assessed using Spearman's correlation coefficient. Mobility levels demonstrated moderate negative correlation with QOL, meaning that as the GMFCS-E&R scores increased, participants became more inactive and had reduced QOL. QOL was positively correlated with attending school. There was a significant moderate correlation between socioeconomic status of

Table 1: Characteristics of the included subjects.

S. No.	Characteristics of the subjects	Values
1	Number of subjects in each age group	
	2-4 years	29
	5-7 years	36
	8-12 years	43
	13-18 years	24
	Total number of subjects	132
2	Number of subjects in each GMFCS-E&R category	
	GMFCS-E&R I	16
	GMFCS-E&R II	24
	GMFCS-E&R III	43
	GMFCS-E&R IV	31
	GMFCS-E&R V	18
3	The average age of the included subjects (mean ± SD)	11.33 ± 7.71
4	Distribution of subjects according to schooling	
	Number of children going to normal school	28
	Number of children going to special schools or centers for special education	82
	Number of children not getting any formal education	22
5	Distribution of the subjects as per the primary caregiver	
	Number of mothers as primary caregivers	111
	Number of fathers as primary caregivers	01
	Number of grandparents as primary caregivers	01
	Number of supporting staff as primary caregivers	19

Abbreviations: GMFCS-E&R, Gross Motor Functional Classification System—Expanded and Revised; SD, standard deviation.

Table 2: Demonstrating values for variables of the caregivers.

Variables of caregivers	Values
Age of the caregiver (years) (mean ± SD)	41.53 ± 6.78
Socioeconomic status of the caregiver	
<5000 SR	14
5000-10,000 SR	66
10,000-20,000 SR	40
>20,000 SR	12
Total number	132
Educational status of the caregiver	
School education	89
College education	27
Postgraduation	12
Doctorate	4
Total	132
BMI (kg/m^2) (mean ± SD)	28.72 ± 6.21

Abbreviations: BMI, body mass index; SD, standard deviation.

Table 3: PedsQL 3.0 CPM components for various age groups and their means, standard deviations, and minimum and maximum values.

PedsQL 3.0 CPM components	Age groups (years)	Mean	SD	Min	Max
Daily activities	2-4	39.3	4.5	18.8	71.8
	5-7	38.8	9.5	17.7	82.9
	8-12	49.2	6.9	10.3	81.2
	13-18	47.6	7.7	30.4	77.1
School activities	2-4	NA	NA	NA	NA
	5-7	49.8	6.7	30.1	75.5
	8-12	63.4	3.9	22.3	91.5
	13-18	55.4	8.2	40.1	95.5
Movement and balance	2-4	21.8	8.1	18.2	49.1
	5-7	54.3	9.2	29.1	73.2
	8-12	69.8	7.1	31.7	95.4
	13-18	47.1	10.8	44.1	90.5
Pain and hurt	2-4	55.3	10.1	23.2	90.7
	5-7	49.1	9.4	31.4	82.2
	8-12	71.5	6.8	41.5	95.1
	13-18	64.4	3.2	59.9	99.1
Fatigue	2-4	42.3	9.1	20.2	67.7
	5-7	39.2	8.2	31.1	66.9
	8-12	66.7	8.1	44.9	99.8
	13-18	46.8	7.3	34.3	98.1
Eating activities	2-4	61.2	6.2	22.1	90.1
	5-7	72.2	8.1	31.2	89.1
	8-12	70.5	6.8	50.5	96.5
	13-18	66.1	9.2	40.3	92.1
Speech and communication	2-4	NA	NA	NA	NA
	5-7	51.2	9.1	31.4	71.7
	8-12	66.6	7.2	40.5	89.2
	13-18	62.8	10.9	55.5	91.2
Total	2-4	44.0	7.6	18.2	90.7
	5-7	50.7	8.6	17.7	89.1
	8-12	65.4	6.7	10.3	99.8
	13-18	55.7	8.2	30.4	99.1

Abbreviations: NA, not applicable; SD, standard deviation.

Table 4: Correlation between quality of life and other parameters like functional capacity, age, and schooling of the subjects.

Correlation parameters	r value	P value
GMFCS-E&R	−0.56	0.01*
Age of the child	0.21	0.14
Schooling	0.45	0.03*
Caregiver's education	0.19	0.23
Socioeconomic status	0.42	0.04*
Age of the caregiver	0.16	0.07
BMI of the caregiver	0.24	0.10

Abbreviations: BMI, body mass index; GMFCS-E&R, Gross Motor Functional Classification System—Expanded and Revised. *Indicates level of significance $P < 0.05$.

the family and QOL of children with CP. There was no significant correlation between QOL and age of the child, age of the caregiver, caregiver's education, and BMI of the caregiver. We present further details of *r* and *P* values in Table 4.

DISCUSSION

CP is a neurodevelopmental disorder that affects children's body function and activity, reducing their QOL. CP is a common physical disability with a high prevalence in Saudi Arabia. This cross-sectional study aims to assess the QOL and factors impacting it among children with CP.

Almuwais et al. conducted a study in Saudi Arabia in 2021 in which parents reported poorer QOL for their children across the domains of school activities, movement and balance, pain and hurt, daily activities, fatigue, and eating activities. However, QOL associated with daily activities, movement and balance, and school activities was particularly low compared to that associated with eating activities (Almuwais et al., 2021). Similarly, in a study conducted by Varni et al., 2006, parents also reported reduced QOL across all domains, but QOL was lower across the daily activities, school activities, movement and balance, and fatigue domains than the eating activities domain (Varni et al., 2006). Our study reported reduced overall QOL across all age groups. Parents reported good QOL in the eating activities domain across all age groups and poorer QOL in the daily activities, movement and balance, school activities, fatigue, and speech and communication domains.

CP is a posture and movement disorder that impacts the trunk, upper limbs, and lower limbs. Tonal issues, reduced strength, and poor trunk control impact movement and balance and reduce the QOL associated with daily activities. Fine motor coordination difficulties negatively impact school activities, while abnormal posture, walking aid use, and lower limb orthosis during walking require more energy consumption, leading to fatigue among children with CP.

Alsaad et al., 2021 reported that children had the lowest QOL scores for school performance, followed by daily activities, and the highest scores in the pain dimension (Alsaad et al., 2021). In our study, the 2- to 4-year-old age group had the lowest overall QOL scores, followed by the 5- to 7-year-old age group and the 13- to 18-year-old age group. The 8- to

12-year-old age group demonstrated the highest overall QOL. This could be explained by the fact that the 2- to 4-year-old age group may have been experiencing developmental delay and were becoming more dependent on their carers to help them complete their daily activities, while the 8- to 12-year-old age group could independently perform these activities. The increased contractures and deformities associated with the 13- to 18-year-old age group, as well as their increased likelihood of having undergone orthopedic surgical procedures, may have contributed to their reduced QOL.

We classified the factors affecting QOL among children with CP, such as the severity of disease, using the GMFCS-E&R. A significant moderate negative correlation was observed between overall QOL and GMFCS scores ($r_s = 0.56$, $P = 0.01$), indicating that greater disease severity was associated with poorer QOL. Thus, disease severity negatively impacts the QOL of children with CP. Similarly, Varni et al. (2006) reported the mean and SD of each PedsQL 3.0 CPM dimension according to disease severity as classified by the GMFCS and found that the QOL of each dimension decreased as disease severity increased.

We observed a significant moderate positive correlation between schooling and overall QOL ($r_s = 0.4$, $P = 0.03$). Therefore, schooling positively impacts the QOL of children, as children attending school had higher QOL scores than those who were not. Children attending school experience socialization and are involved with peer groups for playing and other activities, which could explain why schooling positively impacts their QOL. We found a significant moderate correlation between socioeconomic status of parents and QOL ($r_s = 0.42$, $P = 0.04$) that states that children in the families with lower socioeconomic status demonstrated poorer QOL, while children in the families with middle and higher socioeconomic status demonstrated good QOL. Our results were also supported by a previous study carried out by Didsbury et al. (2016), in which children with chronic diseases from lower socioeconomic status backgrounds demonstrated reduced QOL and children from wealthier socioeconomic status backgrounds demonstrated good QOL. These findings should be observed by healthcare providers, and they should focus on increasing the mobility of the children with CP, thereby increasing the QOL of CP children. Healthcare providers also emphasize on the education of CP children to the family members. Healthcare providers should educate the family members to take the children either to normal schools or special education centers to improve the QOL in these children. Healthcare providers should provide information about the governmental and non-governmental supporting systems in the Kingdom of Saudi Arabia (KSA) to the lower socioeconomic status families, so that lower economic status families with CP children can avail health services to improve the QOL of their children with CP.

This study has several limitations, such as the fact that we did not report QOL based on CP type. Furthermore, we only recruited participants from rehabilitation centers and hospitals in the Abha and Khamis regions of Saudi Arabia. Therefore, generalizing the results to different regions of the country is limited. Many comorbidities and complications associated with CP can also affect the QOL of patients; however, we could not measure these due to practical issues such as the lack of outcome availability and time with the parents. Furthermore, we did not report the QOL based on the functional levels of each age group, as measured using the GMFCS-E&R. Future studies should assess QOL based on the type of CP, recruit samples from different cities in the Aseer region, report QOL according to comorbidities and complications associated with CP, and assess the effects of CP type, comorbidities, and complications on QOL. Further research could also report the QOL of each PedsQL 3.0 CPM dimension based on the functional levels determined using GMFCS-E&R for each age group.

CONCLUSION

The parents of children with CP reported poor QOL for their children across the dimensions of movement and balance, daily activities, and school activities, and high QOL for eating activities. Factors such as functional level negatively impact QOL, while schooling positively impacts the QOL of children with CP. Family is the primary support for CP children; therefore, clinicians should encourage positive parental involvement in rehabilitation to improve the children's QOL. Rehabilitation professionals should inspire parents to allow their children to attend school as this enhances social functioning and QOL. The information on economic burden on the families of CP children will be helpful for policy makers to formulate evidence-based policies in the KSA.

CONFLICTS OF INTEREST

The authors declare that there is no conflict of interest in association with the present study.

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