



Original Article



Psycho-Social Quality of Life Among Children with Cerebral Palsy

Malik Muhammad Naeem^{1*}, Shahzadi Asma Tahseen¹, Imran Azam², Saba Afzal Shaikh³ and Raghab Iqbal⁴

¹Department of Pediatric Medicine, Quaid-e-Azam Medical College, Bahawal Victoria Hospital, Bahawalpur, Pakistan

²Department of Pediatric Medicine, Tehsil Headquarter Hospital, Yazman, Pakistan

³Department of Pediatric Medicine, Akhtar Saeed Medical College, Rawalpindi, Pakistan

⁴Department of Pediatric Medicine, Sheikh Zayed Hospital, Rahim Yar Khan, Pakistan

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***Corresponding Author:**

Malik Muhammad Naeem
 Department of Pediatric Medicine, Quaid-e-Azam Medical College, Bahawal Victoria Hospital, Bahawalpur, Pakistan
naembvh2@qamc.edu.pk

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ABSTRACT

Cerebral Palsy (CP) is known to cause severe physical disability in children. Social, along with mental and physical wellness, constitute a subset of Quality Of Life (QOL) related to general health. **Objective:** To find out the psycho-social QOL among children with CP. **Methods:** This cross sectional study was conducted at the department of Pediatrics Medicine, Sir Sadiq Abbasi Hospital, Quaid-e-Azam Medical College, Bahawalpur, Pakistan from March 2023 to September 2023. Children of either gender between 4-12 years and diagnosed cases of CP were included. Study information like age, gender, weight, area of residence and type of CP were noted. Psycho-social quality of life was assessed as per CP QOL-Child questionnaire. **Results:** In a total of 86 children with CP, the mean age was 7.64±2.63 years while 57 (66.3%) children were aged between 4 to 8 years. There were 64 (74.4%) male and 22 (25.6%) female children. The most common type of CP was spastic quadriplegia, noted in 29 (33.7%) children. The mean psychosocial QOL score was 4.93±1.90. High psychosocial QOL among children with CP was found in 25 (29.1%) patients, whereas there was low quality of life was in 61 (70.9%) children. Relatively younger age was associated with significantly low QOL (p=0.001). Urban place of liven was also associated with low QOL (p=0.001). **Conclusions:** CP affects psycho-social QOL in high proportion of children. Younger age, urban residential affiliation were found to be significant association with low QOL scores.

INTRODUCTION

Cerebral Palsy (CP) is known to cause severe physical disability in children [1]. CP refers to a collection of movement and posture abnormalities caused by an injury or malfunction in the developing brain. A complicated disorder, CP causes a range of motor impairments in different degrees and types [2]. Movement and posture development are thought to be impacted by CP, which might occur during fetal development or in the brain resulting from non-progressive disruptions. An injury to the developing Central Nervous System (CNS), occurring in the uterus, during childbirth, or in the initial life span, are some of the potential factors behind development of CP

[3]. The estimated prevalence of CP in high income countries has declined to 1.6 per 1000 live births while among low income countries, it stands around 3.4 per 1000 live births [4]. The exact prevalence of CP in Pakistan is not known, while local data has identified CP as the most common disability among children [5]. A local study from district Swabi of Khayber Pakhtunkhwa found that among each 1000 live births, 1.22 had CP [6]. Literature shows that spastic CP is the most frequent presentation, followed by athetoid, ataxic, and mixed types [1, 7]. The cerebral injuries that result in the motor dysfunction of CP have no exact treatment, rather, the focus of treatment is on a



variety of interventions such as medication, surgery, and physical therapy, to improve the patient's overall Quality Of Life (QOL) by reducing pain and musculoskeletal limitations [8]. Social, along with mental and physical wellness, constitute a subset of QOL related to general health. Studies reveal that, when compared to their counterparts who do not have CP, children and adolescents with CP have lower functional and psychosocial QOL [9,10].

The rationale behind the planning of this study was that, although standard CP treatments have been linked to increases in child's functional QOL, but their effects on psychosocial QOL are not fully understood. Moreover, not much local data exists regarding QOL of CP children in Pakistan. So, the psychosocial characteristics of CP children remain relatively unknown. Therefore, the objective was to assess the psychosocial quality of life among children with cerebral palsy. The study's findings can help guide better interventions to address psychosocial QOL concerns in these children.

METHODS

This cross-sectional study was performed at the department of pediatric medicine, Civil Hospital, Bahawalpur, Pakistan, from March 2023 to September 2023. A sample size of 86 was estimated considering high social quality of life in children with a CP frequency (p) of 33.8%, $z = 1.96$ for a confidence level ($1-\alpha$) of 95%, and margin of error (e) of 10%, using the formula: $n = z^2 p(1-p)/e^2$ [11]. The inclusion criteria were both male and female children aged 4-12 years and who were diagnosed with CP. The exclusion criteria were children with conditions like neurodegenerative disorders, myopathies, metabolic disorders, neuropathies, and the syndrome of early hypotonia, as such conditions are associated with progressive deterioration or distinct clinical features that can independently and substantially affect psychosocial QOL, thereby confounding the assessment specific to CP. CP was labeled on the basis of medical history and record as an inability to fully control motor skills [11]. A prior approval from the Institutional Ethical and Research Committee was obtained (letter number: 407/DME/QAMC Bahawalpur, dated: 24-09-2020). All of the parents/guardians were asked for informed and written consent after they were briefed about the objective of this research. Demographic information like age, gender, weight, residential status, level of education of caregivers, and type of CP were recorded. Urban area of residence was labeled if the child belonged to a district-level city, while a child who belonged to a below-district-level city was assigned rural area of residence. Types of CP were considered to be: i) Spastic cerebral palsy, as arm and hand on one side of the body are affected by spastic hemiplegia, also known as hemiparesis. Due to tight heel tendons, the child walks later and on tiptoe. Often, the afflicted side's

arm and leg are thinner and shorter. While intellectual ability is typically normal, speech tends to be delayed and may be competent at best. ii) Spastic diplegia or diparesis, characterized by muscle stiffness, mainly in the legs, with less severe effects on the arms and face; hands may also be imprecise. Leg tendon reflexes are overactive. When the foot's bottom is stimulated, toes point upward. Legs that move like scissor arms are caused by tightness in specific leg muscles. Leg braces or a walker may be necessary for children. Language and cognitive assessments were typically normal. iii) Spastic quadriplegia or quadripareisis: The children have a loose neck but excruciating limb stiffness and hardly ever walk. It's challenging to communicate and be understood. Frequent seizures are difficult to control. iv) Dyskinetic cerebral palsy: An abrupt, uncontrollably slow writhing of the hands, feet, arms, or legs. Some kids squirm or drool because of hyperactive facial and tongue muscles. v) Ataxic cerebral palsy: The children are having trouble coordinating and have a wide-based gait when walking. Inability to control voluntary actions, like reaching for a book, or difficulty with rapid or precise movements, like writing or buttoning a garment. vi) symptoms that are mixed up and don't fit into one specific form of CP. Psychosocial QOL was assessed as per CP QOL-Child questionnaire and labeled as low or high [12]. The questionnaire consists of 42 questions in 5 main categories. Caregivers were asked to describe the feelings of their children (according to their perception) about family, friends, participation, communication, health, and special equipment. Questions with rating scales from 1 to 9 (1 is the worst score and stands for very unhappy, while 9 is the best score and stands for very happy), scores of less than or equal to 6 were labeled as low QOL, while scores above 6 were taken as depicting high QOL. Patients were labeled as either having low QOL (scores < 6) or high QOL (scores > 6). All of the necessary information were recorded on a pre-designed proforma. IBM-SPSS Statistics version 26.0, was used to analyze data. The quantitative variable, like age, was represented by the Mean and Standard Deviation (SD). The qualitative variables like gender, area of residence, types of CP, and QOL (as low or high) were described by calculating frequencies and percentages. The analysis of CP QOL-Child was highlighted as scores in terms of mean and standard deviation. Stratification for age, weight, gender, and area of residence was done to address the effect modifiers. A post-stratification chi-square test was applied. Bi variate correlation analysis was performed employing Pearson's correlation test. A p -value < 0.05 was considered standard for significance.

RESULTS

In a total of 86 children with CP, the mean age was 7.64 ± 2.63 years (ranging 4 to 12 years) while 57 (66.3%) children were aged between 4 to 8 years. There were 64 (74.4%) male and

22 (25.6%) female children with male to female ratio of 2.9:1. The mean body weight was 17.74 ± 4.29 kg. Distribution of patients according to type of CP revealed spastic quadriplegia to be the most common type, noted in 29 (33.7%). Table 1 is showing demographic and clinical characteristics of children with CP.

Table 1: Characteristics of Children with CP (n=86)

Study Variables	Categories	Frequency (%)
Age (Years)	4-8	57 (66.3)
	9-12	29 (33.7)
Gender	Male	64 (74.4)
	Female	22 (25.6)
Weight (Kg)	≤20	46 (53.5)
	>20	40 (46.5)
Place of Living	Urban	47 (54.7)
	Rural	39 (45.3)
Type of Cerebral Palsy	Spastic Quadriplegia	29 (33.7)
	Spastic Diplegia	24 (27.9)
	Spastic Hemiplegia	23 (26.7)
	Dyskinetic	3 (3.5)
	Hypotonia	7 (8.2)

The mean psycho-social QOL score was 4.93 ± 1.90 . High psycho-social QOL among children with CP was found in 25 (29.1%) patients, whereas there was low quality of life was in 61 (70.9%) children. Relatively younger age was associated with significantly low QOL ($p=0.001$). Urban place of living was also associated with low QOL ($p=0.001$). Details about the stratification of study variables with respect to psycho-social QOL are shown in table 2.

Table 2: Stratification of Psycho-social Quality of Life with Respect to Study Characteristics (n=86)

Study Variables	Categories	Psycho-social quality of life		p-Value
		High Frequency (%)	Low Frequency (%)	
Age (Years)	4-8	10 (17.5)	47 (82.5)	0.001
	9-12	15 (51.7)	14 (48.3)	
Gender	Male	18 (28.1)	46 (71.9)	0.742
	Female	7 (31.8)	15 (68.2)	
Weight (Kg)	≤20	12 (26.1)	34 (73.9)	0.514
	>20	13 (32.5)	27 (67.5)	
Place of Living	Urban	7 (14.9)	40 (85.1)	0.001
	Rural	18 (46.2)	21 (53.8)	
Type of Cerebral Palsy	Spastic Quadriplegia	12 (41.4)	17 (58.6)	0.471
	Spastic Diplegia	5 (20.8)	19 (79.2)	
	Spastic Hemiplegia	5 (21.7)	18 (78.3)	
	Dyskinetic	1 (33.3)	2 (66.7)	
	Hypotonia	2 (28.6)	5 (71.4)	

Bi-variate correlation analysis employing Pearson's correlation between age and QOL scores revealed a positive and statistically significant relationship with correlation coefficient 0.295 showing $p=0.006$, and the

details are drawn in figure 1.

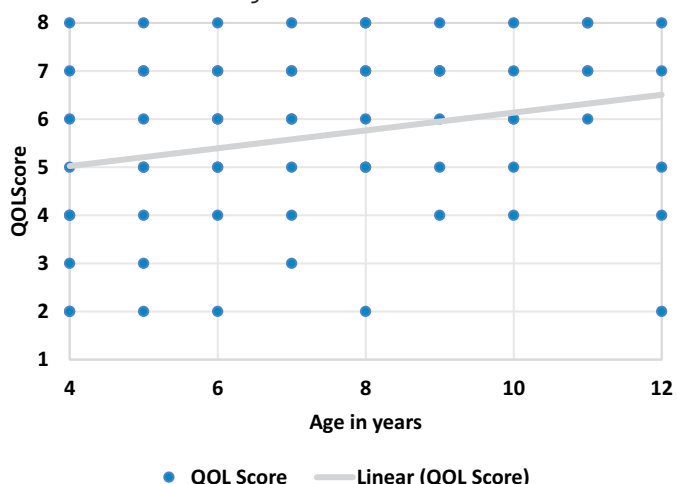


Figure 1: Relationship of Age and QOL Scores in Children with Cerebral Palsy

DISCUSSION

This study assessed psychosocial Quality of Life (QOL) among children with Cerebral Palsy (CP) in a tertiary care center in Bahawalpur, Pakistan. We observed that 29.1% of the children had high psychosocial QOL, while 70.9% had low QOL. Most psychosocial issues identified by parents had persisted for more than a year, and a notable proportion of these problems caused distress to the child (37%) and significantly affected family wellbeing (42%) [13]. Several international studies have also documented a high psychosocial burden among children with CP and their caregivers. An Iraqi study reported poor QOL in 92% of children and high psychosocial burden in over half of mothers [14]. Hend M, in 2021 evaluated various prenatal, perinatal, and postnatal risk factors contributing to the development of cerebral palsy in children [15]. These findings align with previous studies showing that children with CP often experience diminished quality of life, particularly in psychosocial domains. Nurani Gharaborghe et al., in 2015 reported a significant association between gross motor function and overall QOL among children with CP aged 4–12 years, indicating that physical limitations can directly influence psychosocial well-being [16]. Similarly, Tella et al., in 2011 highlighted poor health-related QOL in Nigerian children with CP, emphasizing the broader impact of the disorder on daily functioning and social participation [17]. Although the present results generally align with these international observations, it is important to interpret such comparisons with caution due to significant contextual differences in healthcare infrastructure, social support, and socioeconomic status. Early identification and intervention for CP may be hampered by limited healthcare resources and awareness in the present setting, potentially delaying support and impacting QOL scores,

especially among younger children. In this study, children aged 9–12 years appeared to have better QOL than those aged 4–8, possibly reflecting late recognition of CP or delayed access to services, a pattern that may not be as pronounced in regions with more robust early intervention systems. Age-related differences in HRQOL have been variably reported in the literature, with some studies from Nigeria showing a significant impact of age, while other studies, including those from the United States and elsewhere, have not found a consistent relationship between age and QOL in CP [17–19]. Gender was not found to impact QOL in this study, which is consistent with findings by Bjornson *et al.*, in the United States, but contrasts with an Indian study reporting greater impairment among males [20]. The study's findings are supported by prior research highlighting the multifactorial influences on the quality of life in children with cerebral palsy. Bjornson *et al.*, noted that youth with CP self-reported significantly lower health status and QOL compared to their typically developing peers, particularly in physical and social domains [20]. In an Indonesian population, Lestari *et al.*, identified that factors such as functional ability, parental education, and access to therapy were significantly associated with health-related QOL [21]. Similarly, Vila-Nova *et al.*, emphasized that parents of school-aged children with CP often reported lower QOL scores, particularly in domains related to emotional well-being and social participation [22]. Unique etiologies, such as congenital Zika virus infection, have also been linked with more severely impaired QOL, as demonstrated by Marques *et al.* [23]. In addition to child-specific factors, caregiver burden plays a pivotal role; Tedla *et al.*, in 2023 found that the QOL of caregivers is intricately tied to the child's disability severity and available support systems [24]. A local study by Hanif *et al.*, in 2023 also confirmed that CP significantly compromises multiple dimensions of QOL in Pakistani children, aligning with these study's observation of low psychosocial QOL in a majority of cases [25]. Such discrepancies may reflect local cultural attitudes toward gender and disability, as well as diversity in family and societal support systems. This study utilized the CP-QOL-Child questionnaire for QOL assessment, which is internationally validated and has been employed in studies from Iran, Nigeria, and the United States [16–20]. Regardless of the specific assessment instrument, the literature consistently describes a discernible impact of CP on children's QOL worldwide [17, 18, 20–25]. However, direct comparison of results across countries must be done cautiously due to the aforementioned contextual differences.

This study's limitations include its single-center design, modest sample size, and the lack of detailed assessment of parental, familial, or socioeconomic factors that may

influence QOL. Additionally, the specific regional context may limit the generalizability of these findings within or outside Pakistan. Future studies should consider multicenter designs and broader assessment of environmental, parental, and social variables to better understand the determinants of QOL in children with CP

CONCLUSIONS

CP affects psycho-social QOL in high proportion of children. Younger age, urban residential affiliation were found to be significant association with low QOL scores.

Authors' Contribution

Conceptualization: MMN, SAT, SAS, RI

Methodology: MMN, SAT, IA

Formal analysis: IA

Writing and Drafting: MMN, SAT, SAS, RI

Review and Editing: MMN, SAT, IA, SAS, RI

All authors approved the final manuscript and take responsibility for the integrity of the work

Conflicts of Interest

All the authors declare no conflict of interest.

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