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Original Research Article

Assessment of physical functioning domain on quality of life of children with cerebral palsy-experience in rural Bangladesh

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ABSTRACT

Background: Cerebral palsy (CP) is the most prevalent health condition linked to childhood disability in Bangladesh. This study was intended to evaluate the physical functioning domain of quality of life (QoL) of children with CP using Peds QLTM inventory in a tertiary care hospital. The aim of this study was to find out physical aspects of the child's QoL by using PedsQL™ inventory (physical, emotional, social, schooling), to identify co-morbidities, socio demographic profile of child and parents and to find out relationship between physical functioning domains of QoL score with types, co-morbidities and of socio demographic characteristics.
Methods: To evaluate health related QoL (HRQOL), PedsQL 4.0, a generic tool, validated in Bangladesh was applied to and the questionnaire was answered by parents. Main outcome variable was physical functioning.
Results: Majority of patients (28.16%) have both speech impairment and behavior problem. Intellectual disability was found 13.79%, 14.94% had epilepsy. Overall physical functioning summary score (PFSS) was 21.65 (95% CI). Multiple regression analysis of generic scale core and the variables associated independently with QoL. No statistically significant difference was found between types, co-morbidities of CP, father's and mother's education, family income, place of residence with physical domains of QoL score. Among all the types of CP only quadriplegic CP had significant effect on physical functioning score with ($p<0.05$), but this does not explain the variations in physical functioning score well (R square=0.208).
Conclusions: The results of this study concluded that QoL pertaining to physical functioning domain in children with CP was found low which was most significant among children with quadriplegic CP. Most of the patients had speech impairment and behavior problem.

Keywords: Quality of life, Cerebral palsy, Children

INTRODUCTION

Cerebral palsy (CP) is a group of permanent disorders of movement and posture that lead to activity limitations and are caused by non-progressive disturbances in the developing fetal or infant brain.[1] It is the leading cause of physical disability in children worldwide.[2] Although the global burden of CP is difficult to quantify, particularly in low- and middle-income countries (LMICs), its prevalence is estimated to be 5 to 10 times higher in

LMICs than in high-income countries (HICs).[3] Most individuals with CP experience associated impairments. Around half live with chronic pain and/or intellectual disability, and more than one-third are unable to walk. These figures may be even higher in LMIC settings.[4,5] The global incidence of CP ranges from 1.5 to 2.5 per 1,000 live births, while a recent population-based study estimated its prevalence at 3.4 per 1,000 children.[6,7] In many cases, motor function is severely impaired, and rates of speech, visual, and hearing impairments, along with epilepsy, are higher than global averages.[7,8] Among premature infants and those with extremely low birth weight, CP incidence rises significantly to between 40 and 100 per 1,000 live births.[6] An Indian study reported a CP prevalence of 2.83 per 1,000 children aged 0 to 19 years.[9] In Bangladesh, childhood CP cases have been increasingly reported. For example, a report from the pediatric unit of the centre for the rehabilitation of the paralysed (CRP) noted 1,178 cases of childhood impairment between June 2006 and July 2007. Between 2009 and 2011, 91% of pediatric disability cases at CRP were diagnosed as CP.[10] The world health organization (WHO) defines QoL as an individual's perception of their position in life, in the context of their cultural and value systems, goals, expectations, and concerns.[11] In pediatric populations, QoL is a subjective, multidimensional construct that reflects a child's functional ability and psychosocial interaction within their environment and family.[12] In Bangladesh, the development of public health infrastructure and disability services is still at a critical and emerging stage.[13,14] As such, evaluating the QoL of children with CP is vital for shaping targeted health interventions and policies.[15] One of the most widely used tools to assess pediatric HRQoL is the PedsQL™ version 4.0 generic core scales.[16,17] This instrument evaluates physical, emotional, social, and school functioning, providing a comprehensive view of the child's well-being.[18,19] While the HRQoL of children and adolescents with CP in Bangladesh remains largely unexamined, studies in other LMICs have shown significantly lower QoL scores among children with CP compared to their typically developing peers.[20] Interestingly, some studies from HICs have reported that adolescents with CP may have HRQoL comparable to that of their peers without disabilities.[21] Given the limited data in the Bangladeshi context, this study was undertaken to explore the socio-demographic profiles of children with CP and their parents, to examine the types and co-morbidities associated with CP, and to assess how the physical functioning domain of QoL is affected, using the PedsQL™. The study also aimed to evaluate relationships between QoL domains and socio-demographic characteristics, types of CP, and co-morbid conditions.

METHODS

This cross-sectional study was conducted at the BIRDEM general hospital-2, Dhaka, Bangladesh. The study spanned a period of six months, from March to August 2019. It focused on evaluating the HRQoL among children diagnosed with CP. Participants were recruited from the outpatient department (OPD) of Shishu Bikash Kendra and the inpatient department (IPD) of the department of paediatrics. A purposive sampling technique was employed to select the study participants.

Inclusion criteria

Children aged 2 to 7 years and diagnosed with CP were included.

Exclusion criteria

Children with severe medical illnesses such as heart failure, malignancy, or chronic kidney disease and with severe mental retardation along with CP were excluded.

Data collection

Data were collected through interviews with their parents or primary caregivers, considering the neurological developmental delays commonly associated with CP. HRQoL was assessed using the PedsQL 4.0 generic core scales, a tool validated for use in Bangladesh. Due to communication difficulties in children with CP, responses were provided by their parents. For children aged 2-4 years, the questionnaire consisted of 21 items, while for those aged 5-7 years, it contained 23 items, both covering key domains such as physical health, energy level, discomfort, and daily functioning.

Each item was rated on a five-point Likert scale (0=never a problem to 4=almost always a problem). Scores were reverse-coded and transformed linearly to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0), where higher scores indicated better QoL. Scale scores were calculated as the mean of all answered items. If more than 50% of the items in a particular domain were missing, that domain's score was not computed.

Statistical analysis

All collected data were reviewed, checked for consistency, and cleaned before analysis. Descriptive statistics including mean, standard deviation, frequency, and percentage were used to summarize the data. Chi-square tests were employed for comparing categorical variables where appropriate. Data analysis was performed using SPSS for Windows, version 23. A $p<0.05$ was considered statistically significant, and all findings were reported at a 95% confidence interval.

Ethical consideration

The study protocol received ethical clearance from the ethical review committee (ERC) of BIRDEM. Informed written and verbal consent was obtained from all participating parents, in both Bangla and English. Participants were assured of the confidentiality of their

responses and were given freedom to skip any question or withdraw from study at any time without consequence.

RESULTS

This study included 60 CP patients, predominantly male (male 37 and female 23), with a mean age of 44.83±20 months. Most (46.7%) were aged 24-35 months. About 61.7% were male, with a male-to-female ratio of 1.6:1. Over half of the families (55%) had one child. The majority (61.7%) were from rural areas. Most (90%) were accompanied by mothers; only 5% had single parents. About 76.7% of fathers completed primary education, and 65% of mothers completed secondary education. Over half (58.6%) of fathers were service holders, and 88.1% of mothers were housewives. Around 43.3% of patients were from lower-middle income families (Table 1). Table 2 showed that 36.7% of the children had spastic quadriplegia, 21.7% spastic diplegia, 18.3% spastic hemiplegia, 13.3% hypotonia, and 10% dyskinetic CP. Regarding comorbidities, 28.16% had both speech impairment and behavior problems. IQ assessment was done in 24 of 60 patients; 13.79% had intellectual disability, 14.94% epilepsy, 8.05% vision impairment, 4.02% hearing impairment, and 2.87% had feeding problems. Regarding physical functioning, 75% had difficulty bathing independently, 68.3% with lifting objects, and 53.3% with running or participating in sports or exercise-reported as 'Almost always'. These were the most affected areas (Table 3). The QoL PFSS was 21.65 (95% CI), the lowest among domains (Table 4). Table 5 showed that only quadriplegic CP had a significant impact on physical functioning score (p=0.025). Children with quadriplegic CP scored 0.425 lower than those with hypotonic CP (reference). Comorbidities had no significant effect on physical functioning. Children from rural areas had, on average, 10.645 units higher physical functioning scores than those from urban areas. If the father's education was secondary or below, the child's score was 3.516 units lower than those whose fathers had primary or less education. Children from affluent families (income >83,333 BDT) scored 31.891 units higher than those from low-income groups (7,500-16,666 BDT). Children whose mothers were graduates/higher had 6.097 units higher scores than those whose mothers had primary or less education. However, model showed no significant effect (p=0.77), and R^2=0.072 indicated only 7% variance explained in physical functioning score (Table 6).

Table 1: Demographic characteristics of the study patients, (n=60).

Parameters		N	Percentage (%)
Age (in months)	24-35	28	46.70
	36-47	9	15.00
	48-59	6	10.00
	60-72	8	13.30
	73-84	9	15.00
Gender	Male	37	61.70
	Female	23	38.30
Place of residence	Urban	23	38.30
	Rural	37	61.70
Caregiver	Mother	54	90.00
	Father	4	6.70
	Other	2	3.30
Number of children in family	1	33	55.00
	2	18	30.00
	3	6	10.00
	4	3	5.00
Single parent	No	57	95.00
	Yes	3	5.00
Father's education	Primary or below	46	76.70
	Secondary or below	14	23.30
Mother's education	Primary or below	12	20.00
	Secondary or below	39	65.00
	Graduate or more	9	15.00
Father's occupation	Day labor	4	6.80
	Service holder	34	58.60
	Businessman	20	34.50
Mother's occupation	Housewife	52	88.10
	Service holder	7	11.90
Monthly income of family (BDT)	Lower income	9	15.00
	Lower-middle income	26	43.30
	Upper-middle income	23	38.30
	High income	2	3.30

Table 2: Distribution of patients by types and co-morbidities of CP, (n=60).

Types		N	Percentage (%)
Spastic	Quadriplegic	11	18.30
	Hemiplegic	13	21.70
	Diplegic	22	36.70
Dyskinetic		6	10
Hypotonic		8	13.30
Co-morbidity			
Intellectual disability		24	13.79
Epilepsy		26	14.94
Feeding difficulty		5	2.87
Hearing impairment		7	4.02
Speech impairment		49	28.16
Behavior problem		49	28.16
Vision impairment		14	8.05

Table 3: Distribution of study patients by physical functioning, (n=60).

Problem with physical functioning during last one month	Never	Almost never	Sometimes	Often	Almost always
	N (%)	N (%)	N (%)	N (%)	N (%)
Walking >1 block (1 block=100 m)	19 (31.7)	1 (1.7)	3 (5.0)	6 (10.0)	31 (51.7)
Running	18 (30.0)	1 (1.7)	5 (8.3)	4 (6.7)	32 (53.3)
Participating in sports/ exercise	15 (25.0)	1 (1.7)	8 (13.3)	4 (6.7)	32 (53.3)
Lifting something	2 (3.3)	-	10 (16.7)	7 (11.7)	41 (68.3)
Taking a bath by him/herself	5 (8.3)	1 (1.7)	2 (3.3)	7 (11.7)	45 (75.0)
Doing chores around the house	2 (11.1)	-	3 (16.7)	3 (16.7)	10 (55.6)
Having hurts or aches	27 (45.0)	2 (3.3)	23 (38.3)	6 (10.0)	2 (3.3)
Low energy level	4 (6.7)	-	16 (26.7)	17 (28.3)	23 (38.3)

Table 4: Base line characteristics of QoL score.

Parameters	Mean	±SD	Median
PFSS, (n=60)	32.5	26.29	21.65

Table 5: Multiple linear regression analysis of types and co-morbidities of CP on PFSS.

Variables	Beta coefficient[a]±standard error	P value
Constant	40.625 (±8.570)	0
Hemiplegic	0.048 (±11.263)	0.777
Diplegic	0.051(±10.892)	0.768
Quadriplegic	-0.425 (±10.007)	0.025
Dyskinetic	-0.112 (±13.091)	0.460
Constant	51.593 (±10.299)	0
Epilepsy	-0.158 (±7.226)	0.256
Feeding difficulty	-0.119 (±11.736)	0.345
Hearing impairment	-0.142 (±7.973)	0.314
Speech impairment	-0.080 (±8.962)	0.548
Behavior problem	-0.106 (±8.541)	0.408
Vision impairment	-0.206 (±8.555)	0.143

Table 6: Multiple linear regression analysis of place of residence, father's and mother's education and monthly family income on PFSS.

Variables		Beta coefficient ± Standard error	P value
Constant		27.282 (±11.025)	0.017
Place of residence	Urban (reference)	-	
	Rural	10.645 (±8.020)	0.19

Continued.

Variables		Beta coefficient ± Standard error	P value
Father's education	Primary or below (reference)	-	
	Secondary or below	-3.516 (±9.385)	0.709
Mother's education	Primary or below (reference)	-	
	Secondary or below	0.412 (±9.399)	0.965
	Graduate or above	6.097 (±13.222)	0.747
Monthly family income	Lower income	-	
	Lower-middle income	-2.061 (±11.056)	0.853
	Upper-middle income	-4.881 (±11.856)	0.682
	High income	31.891 (±23.207)	0.175

DISCUSSION

Children with CP in LMICs often face substantial challenges in physical functioning, which can profoundly influence their overall QoL.[20] This cross-sectional study evaluated the QoL among children diagnosed with CP, incorporating an analysis of socio-demographic characteristics of both children and their caregivers, classifications and associated co-morbidities of CP, and the relationship of these variables with specific QoL domains. Similar international studies have also assessed parent-reported QoL across various subjective domains for representative CP populations.[22-24] In total, 60 parents of children aged 2-7 years were interviewed using a structured questionnaire. The mean age of children was 44.83±20.646 months, with a male-to-female ratio of 1.6:1, indicating slight male predominance-consistent with other studies: Davis et al (1.2:1), Okurowska et al (1.3:1), McCullough and Parkes (1.2:1), Silva et al (1.3:1), Shrestha et al (1.5:1), and Vles et al (1.6:1).[22,25-31] CP is known to be more common in males, which aligns with the current findings.[22] Frota et al reported a similar mean age of 46.7±21.424 months.[22] This age group was selected based on the CP-PedsQL version 4.0 module, as neurological development in most CP children is delayed. In this study, over half (55%) of families had a single child, similar to Frota et al (69.4%).[22] Most patients (61.7%) were from rural areas, consistent with studies reporting higher CP prevalence in rural settings.[32] About 95% had both parents, aligning with Vles et al (91%), while only 5% had a single parent, also supported by Vles et al (4%).[31] Mothers were the primary caregivers in 90% of cases, and only 6.7% were fathers-comparable to Mohammed FMS et al who found 92.3% mothers and 1.5% fathers as caregivers.[33] In this study, 58.6% of fathers were service holders, close to Frota et al 82.2%, and 88.1% of mothers were housewives, similar to Mohammed et al (89.2%).[22,23] About 43.3% of patients came from middle-class families, comparable to Dobhal et al (49%). Similar findings on mothers being homemakers were also reported by the Chalipat et al (63.3%), Frota et al, Corbella et al and Shrestha et al.[22,25,30,34,35] Regarding socioeconomic characteristics, a similar study on children with CP in southern regions found 50% of fathers had incomplete elementary education, aligning with this study where 76.7% of fathers completed primary and 65% of mothers completed secondary education. Shrestha et al reported 50% of mothers had secondary education.[30] Morales et al also found low parental education levels.[36] In this study, most patients (81.7%) attended the outpatient department, and 56.7% were diagnosed between 6-12 months. Additionally, 26% were diagnosed at 12-18 months and 13.3% at 19-24 months. The mean age since diagnosis was 14.07±6.719 months. Other studies reported varying diagnosis ages, typically between birth and 3 years, with 38.7% diagnosed at 2-6 months and 35.5% at 7-12 months.[21] Shrestha et al found 83.3% diagnosed within 0-5 years.[30] McCullough et al also reported 80% diagnosed below age 5, as early motor signs may resolve in some children.[28] In this study, 76.7% had quadriplegic CP, including 36.7% spastic quadriplegia, 21.7% spastic diplegia, and 18.3% spastic hemiplegia. Hypotonic and dyskinetic CP accounted for 13.3% and 10%, respectively. Shrestha et al reported 61.9% with spastic CP.[30] Okurowska et al found 45% spastic quadriplegia, 37.5% hemiplegia, and 17.5% diplegia. Parisi et al observed 50% quadriplegia, 13.8% diplegia, 11.11% hemiplegia, and 8.33% dyskinetic CP.[27,37] Similar findings were reported by Shimard et al and Dobhal et al with spastic quadriplegia as the most common type.[34,38] Among the study patients, 28.16% had both speech impairment and behavior problems. Intellectual disability was found in 13.79%, epilepsy in 14.94%, vision impairment in 8.05%, hearing impairment in 4.02%, and feeding problems in 2.87%. Most respondents (85.7%) had speech impairment. Shrestha et al reported 33.3% with epilepsy and 21.4% with behavior problems.[30] Regarding physical functioning, major issues that "almost always" occurred included difficulty bathing (75%), lifting objects (68.3%), running (53.3%), walking (51.7%), and doing chores (55.6%). Frota et al similarly reported walking and running difficulties in 75.8% and 83.9%, respectively, as children with CP often remain dependent on caregivers for daily activities.[22] The present study showed a PFSS of 32.5±26.65. Mohammed et al reported the lowest score (39) in the physical functioning domain.[33] Arnaud et al noted a physical well-being score of 55, while Dobhal et al found a score of 18.5.[34,39] In our study, the lowest median score was 21.65 in this domain. Multiple regression analysis showed only quadriplegic CP had a significant effect on the physical functioning score (p=0.025), with 0.425 units lower score than hypotonic CP. However, the model had limited

explanatory power (R^2=0.208), suggesting other unmeasured factors influence physical functioning. This aligns with Almqvist et al who found weak correlations between disability types and QoL.[40] Similarly, regression analysis of co-morbidities showed no significant effect, although the model itself was significant (p=0.041, R^2=0.212). Socio-demographic factors also had no significant impact on physical functioning score, consistent with other international studies.[41] Previous research on general pediatric populations or specific groups like obese children found higher QoL scores among children with higher family income, parental education, employment, and intact families.[42-46] Educated parents often understand their child's condition better, improving care.[34] However, a European study showed an inverse relationship between parental education and QoL domains, indicating a complex dynamic.[47] The observed low QoL scores in our study are consistent with findings from Nigeria and Latvia, but differ from a European survey based on children's self-reports.[47-49]

Limitations

This study was limited by its cross-sectional design, which precludes inference of causality between physical functioning and quality of life in children with CP. The use of purposive sampling from a single tertiary care center may reduce generalizability to broader rural populations. Reliance on caregiver-reported data may introduce response bias, particularly given communication difficulties in the pediatric population. Furthermore, the study did not account for the severity grading of comorbidities, which may have influenced physical functioning outcomes.

CONCLUSION

The results of this study concluded that QoL pertaining to physical functioning domain in children with CP was found low which was most significant among children with quadriplegic CP. Most of the patients had speech impairment and behavior problem.

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