RESEARCH ARTICLE

Relationship between gross motor function of cerebral palsy children and quality of life of their primary caregivers

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Abstract

Objective: To determine the relationship between gross motor function of children with cerebral palsy and quality of life of their primary caregivers.

Method: The cross-sectional analytical study was conducted from December 2020 to August 2021 at the Sindh Institute of Physical Medicine and Rehabilitation and the Rabia Moon Trust, Karachi, and comprised children with cerebral palsy and their caregivers. The children were assessed on the basis of Gross Motor Function Measure-66 and Gross Motor Functional Classification System, while the caregivers were asked to complete the self-administered World Health Organisation Quality of Life-BREF questionnaire. All the categorical variables were presented through frequencies and percentages. Spearman's Correlation was applied to evaluate the correlation. Data was analysed using SPSS 16.

Results: Of the 43 children, 26(60.5%) were male and 17(39.5%) were females. The overall mean age was 5.70±1.820 years. Among the caregivers, 40(93%) were females and 3(7%) were males. The mean age of the caregivers was 27.70±4.77 years. None of domains of quality of life showed significant correlation with total score of Gross Motor Function Measure-66 ($p>0.05$).

Conclusion: The disease severity among children with cerebral palsy was not a factor associated with quality of life of the caregivers. The physical health was relatively lower among the caregivers, but it was not associated with motor disabilities.

Keywords: Caregiver burden, Child development disorders, Correlation, Developmental, Disabilities, Family caregivers. (JPMA 73: 78; 2023) **DOI: 10.47391/JPMA.6303**

Submission completion date: 13-04-2022 — **Acceptance date:** 25-08-2022

Introduction

Cerebral palsy (CP) is globally considered the most prevalent paediatric condition causing physical disability.[1] In general, CP prevalence rate is 2.5/1000 livebirths, although in developing countries it may vary from 1 to 6 per 1000 livebirths.[2] CP is characterised as permanent disruption in a neonatal brain which subsequently causes permanent movement and postural disorders, causing disabilities and activity limitations.[3] The associated conditions commonly found in population with CP are cognitive disability (40%), epilepsy (30%), complex motor disorders (20%), altered vision (16%), under-nutrition and other related health problems, such as gastrointestinal disturbance, increased weight and undernourishment (15%), and hydrocephalus (14%).[4] The severity levels of the cognitive disablements and movement difficulties may vary in every child, and they are less likely to participate in different life areas and self-care activities. These movement restrictions lead to dependency on the caregivers for mobility and self-care, and affect their level of involvement in carrying out everyday tasks in activities of daily living and ultimately influence their quality of life (QOL).[5]

Pakistan is considered a lower middle-income country (LMIC), and there are fewer opportunities for a CP child to acquire appropriate treatment at a rehabilitation centre by a multidisciplinary team. Treatment is provided sporadically by rehabilitation teams while the primary caregivers, specifically mothers, provide the care and support for mobility. It becomes very challenging for caregivers to deal with their child's long-term health problems efficiently and effectively, and to manage all the requirements of everyday life. Consequently, the task of providing care to children with multiple impairments and functional limitations on their own can be problematic and challenging for the caregivers. Providing this amount of care may pose burden on both physical health and psychological wellbeing of the caregivers of children with lifelong disabilities.[6] Several studies have provided sufficient evidence regarding mothers having children with disabilities, like CP, experiencing psychological

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health problems, particularly depressive disorders, compared to those with healthy children.[7]

Providing daily care and support to CP children can potentially become straining and exhausting for physical and mental health of the caregivers.[8] Parents of CP children not only have to deal with psychological and physical health problems, but they also face social isolation. Due to their inability to participate in social life events, caregivers are not only stigmatised, but also face conflicts within the immediate family and social circle. Besides, they also must face physical stress, including reduced sleep, musculoskeletal aches and pains, and high blood pressure (BP).[9] Point of concern is where the caregivers' burden increases to the extent at which their QOL is compromised, and they are no longer able to provide quality care to CP children. Despite its significance, the caregiver's health is a poorly discussed topic in relation to paediatric disability.[10] The current study was planned to correlate the severity of disease and type of CP with QOL of their caregivers, particularly with respect to motor functions.

Subjects and Methods

The cross-sectional analytical study was conducted from December 2020 to August 2021 at the Sindh Institute of Physical Medicine and Rehabilitation and the Rabia Moon Trust, Karachi. After approval from the institutional ethics review board of the Dow University of Health Sciences (DUHS), Karachi, the sample size was calculated using OpenEpi 3.0[11] confidence level 95%, power 90% and margin of error 5%. The sample was calculated keeping Gross motor functions measure (GMFM) score of CP children 18.7±31.0 and caregivers' QOL score 58.9±73.0.[12] The sample was raised using non-probability purposive sampling technique. Those included were CP children aged 4-12 years who had been diagnosed by a neurologist. Caregivers included a parent or any other relative who looked after the CP child for 6 hours or more every day. Children with other musculoskeletal disorders, like Duchene muscular dystrophy, children with other behavioural disorders, like autism, children with other neurological conditions, like neuropathies and Erb's palsy, and children with other birth defects, like heart defects, Down Syndrome (DS), and neural tube defects, were excluded. Among the caregivers, those excluded were those having another child with physical or mental disability, having severe or chronic health issues, like cardiovascular accident, diabetes mellitus etc., and history of any psychological condition before CP was diagnosed in the child.

The caregivers along with children who fulfilled the inclusion criteria were enrolled after taking informed consent in Urdu. World Health Organization Quality of Life-Bref (WHOQOL-BREF), self-administered questionnaire was provided to the caregivers for QOL assessment.[13] The questionnaire was explained to the caregivers when needed. The subtypes of CP were classified on the basis of diagnosis by neurologist and topographical pattern of motor impairment. The 5-level classification system, Gross Motor Function Classification System--Expanded and Revised (GMFCS-E&R) was assessed with the help of Gross Motor Function Classification System (GMFCS)-Family Report Questionnaire to assign different level of functional mobility to the individual child.[14] The children who were able to walk and perform all the tasks according to their age group (limitations of speed, balance and poor coordination were present), were assigned Level I, while those with limited voluntary control of limb movements and extreme difficulties with trunk posture were assigned Level V.[15] General motor functions were evaluated by the 66-item Gross Motor Function Measure (GMFM-66) tool. The assessment process took about 45 minutes, and maximum of three trials were allowed. Verbal encouragement and demonstration were used to test all the items while spontaneous movements were accepted. Complete assessment required a mat, adjustable bench, stairs with at least 5 steps and toys.[16]

Data was analysed using SPSS 16. Frequencies and percentages were calculated for gender, CP type, and age of children, while means and standard deviations were calculated for GMFM-66 and QOL scores. Data, tested with Shapiro-Wilks test, was not normally distributed ($p<0.05$). Spearman's Correlation was applied to evaluate the association between QOL of the caregivers and gross motor function of the CP children. Analysis of variance (ANOVA) was used to analyse the association involving GMFCS levels, CP types, age, gender of children and different QOL components of caregivers. $P<0.05$ was considered statistically significant.

Results

Of the 43 caregivers, 40(93%) were females and 3(7%) were males. The overall mean age was 27.70±4.77 years (Table-1). Among the CP children, 26(60.5%) were male and 17(39.5%) were females. The mean age of the children was 5.70±1.820 years (Table-2). Descriptive statistics of caregivers' QOL and CP children's motor function level under different domains and in total were noted separately (Table-3).

Physical health was non-significantly ($p>0.05$) correlated to lying and rolling ($r=0.179$), sitting ($r=0.179$), crawling

Table-1: Characteristics of caregivers of children with cerebral palsy (CP).

Characteristics	Frequency	Percentages
Gender of Caregiver		
Male	3	7.0
Female	40	93.0
Relationship with child		
Mother	37	86.0
Father	3	7.0
Other	3	7.0
Marital Status		
Married	41	95.3
Widow	2	4.7
Educational Status		
Illiterate	17	39.5
Primary School	11	25.6
Secondary	9	20.9
Higher Secondary	5	11.6
Graduate	1	2.3
Number of Children		
One	8	18.6
Two	11	25.6
Three	11	25.6
Four or more	13	30.2
Employment		
Employed	10	23.3
Unemployed	33	76.7

Table-2: Characteristics of children with cerebral palsy (CP).

Characteristics	Frequency	Percentage
Gender of Child		
Male	26	60.5
Female	17	39.5
Type of cerebral palsy		
Spastic	21	48.8
Athetoid	1	2.3
Flaccid	11	25.6
Ataxic	2	4.7
Mixed	8	18.6
GMFCS Level		
II	8	18.6
III	12	27.9
Iv	16	37.2
V	7	16.3

GMFCS: Gross motor function classification system.

and kneeling (r=0.179), standing (r=0.179), walking, running and jumping (r=0.179), and with GMFM-66 score (r=0.156). Psychological health was also non-significantly (p>0.05) correlated to lying and rolling (r=0.146), sitting (r=0.146), crawling and kneeling (r=0.146), standing (r=0.146), walking, running and jumping (r=0.146), and with GMFM-66 score (r=0.097).

Social relationships domain showed non-significant (p>0.05) correlation with all GMFM-66 domains (r=-0.014) and with total GMFM-66 score (r=0.173). The environment sub-factor also showed non-significant (p>0.05) correlation with all GMFM-66 sub-factors (r=-0.109) and with total GMFM-66 score (r=0.238). Total score of WHOQOL-BREF also non-significantly correlated with all GMFM-66 sub-factors (r=-0.175) and with total GMFM-66 score (r=0.221).

Discussion

Among 43 CP children, nearly half were spastic, and the majority had GMFCS level IV, while most of caregivers were mothers and unemployed. The study proved no significant association between GMFM-66 scores of CP children and QOL scores of their primary caregivers, which indicates that the QOL of caregivers is not influenced by the disease severity of their CP child. Mean

Table-3: Descriptive statistics of outcome measures.

Outcome measures	Mean	Median	Std Deviation	Minimum	Maximum	Percentiles		
						25	50	75
WHOQOL-BREF								
Physical health	11.9734	12.0000	1.81111	8.57	17.14	10.8571	12.0000	13.1429
Psychological	12.2016	12.0000	1.90535	8.00	16.00	10.6667	12.0000	14.0000
Social relationships	13.3333	13.3333	1.64590	10.67	17.33	12.0000	13.3333	14.6667
Environment	12.2442	12.0000	1.72300	8.50	15.50	11.5000	12.0000	14.0000
Total score	79.6512	80.0000	9.63101	62.00	106.00	73.0000	80.0000	87.0000
GMFM								
Lying & rolling	22.2070	23.5294	2.76374	13.73	23.53	21.5686	23.5294	23.5294
Sitting	18.8760	20.0000	2.34918	11.67	20.00	18.3333	20.0000	20.0000
Crawling & kneeling	26.9657	28.5714	3.35597	16.67	28.57	26.1905	28.5714	28.5714
Standing	29.0400	30.7692	3.61412	17.95	30.77	28.2051	30.7692	30.7692
Walking, running & jumping	15.7300	16.6667	1.95765	9.72	16.67	15.2778	16.6667	16.6667
Total score	22.5637	23.9073	2.80813	13.95	23.91	21.9151	23.9073	23.9073

WHOQOL-BREF: World Health Organisation Quality of Life-Bref, GMFM: Gross motor functions measure.

scores of physical health of caregivers were lower than all other domains, while the social relationships domain had higher mean scores. This finding is contrary to the study which reported that functional limitations of CP children had a linear relationship with QOL of their primary caregivers.[12] However, the study provided results on the basis of a different outcome tool, the 8 domains of Short Form-36 (SF-36), while the motor functions of CP children were assessed with GMFM-88 and Functional Independence Measure (FIM).[12] The difference in the findings might be due to the difference in assessment tools and their application.

There is enough literature supporting the theory that disease severity among CP children can affect QOL of their primary caregivers,[17] but only few have reassessed the change in QOL scores of caregivers after improvement in gross motor functions of children who underwent an intensive rehabilitation programme. Parallel to the results of the current study, Prudente CO et al. reported that with improvement of gross motor functions of CP children there was little or no significant improvement in QOL of their mothers. The study included mothers along with their CP children who were receiving physical therapy. The GMFM scores of children and QOL scores of mothers were correlated before and after 10 months of treatment.[18]

Another study used multiple tools, including WHOQOL-BREF, Beck Depression Inventory (BDI) the Caregiver Difficulties Scale (CDF) and the Fatigue Severity Scale (FSS), on 203 mothers of CP children to evaluate the factors associated with QOL. The burden of care, depression, fatigue and type of CP could be the predicting factors of QOL among mothers.[19]

As such, it can be said that gross motor functions cannot be the only factor to reduced QOL scores among the caregivers. Another study supported this theory by identifying unemployment of mothers and cognitive disabilities of children as the major factors causing worst QOL scores among the mothers.[20] There are multiple studies reporting lower psychological and physical health scores among the caregivers due to disease severity among their CP children,[21-23] which is in conflict with the current findings. All the studies evaluated gross motor functions of children by using different tools, but in this present study, GMFM-66 along with GMFCS level was used which is more specific to CP.[24] Tseng M.H. et al. studied various factors affecting the QOL of CP children and their caregivers, and concluded that caregivers' QOL is not only affected by characteristics of children, but also the caregivers' personal characteristics that may include psychological wellbeing, financial status, age, marital status and other environmental conditions.[25]

The current study is the first to use GMFM-66 to assess gross motor functions of CP children. The study had a strict inclusion criterion which didn't include extremes of ages; <4 years and >12 years. Also, the study was carried out in more than one settings, which has improved the generalisability of the findings as it had participants from all types of socioeconomic background.

The current study also has its limitations as it was conducted in a single city with a small sample size. All the studies in literature cited above had sample size greater than the present one. As QOL is a complex measure, it is affected by various factors, including environment, state of mind, etc., and it is difficult to say that the responses given by the participants were exactly how they generally felt. Finally, this study was conducted at one point in time and could not assess any QOL improvement among the caregivers with improvement of the functional level of their children.

Conclusion

Disease severity of CP children was not found to be associated with QOL of the caregivers. QOL is a multidimensional variable which needs to be assessed with all possible determinants.

Disclaimer: None.

Conflict of Interest: None.

Source of Funding: None.

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