

# Prevalence of depression and quality of life in primary caregiver of children with cerebral palsy

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## ABSTRACT

**Objective:** Study the correlation of depression and quality of life (QoL) in primary caregivers (mothers) of children with cerebral palsy (CP). **Methods:** An observational cross-sectional study was conducted on a total of 203 primary caregivers (mothers) of children with CP. The depression and QoL in the caregivers were assessed using the Montgomery and Asberg Depression Rating Scale and World Health Organization Quality of Life Instrument (WHOQOL-BREF) (physical, psychological, social and environmental domains), respectively. The child's gross motor function level was determined using the Gross Motor Functional Classification System-Expanded and Revised (GMFCS-ER). The association of depression and QoL in mothers to functional limitation in children were assessed. For statistical methods,  $P < 0.05$  was considered significant. **Results:** The severity of the depression showed a statistically significant negative correlation with the physical domain ( $r = -0.498, P < 0.0001$ ), psychological domains ( $r = -0.486, P < 0.0001$ ), social relationships ( $r = -0.165, P = 0.019$ ) and environmental domains ( $r = -0.195, P = 0.005$ ). The mean QoL domains scores showed a decreasing trend with increasing motor dysfunction of the child, with a statistical association for physical ( $r = -0.327, P < 0.0001$ ) and psychological domains ( $r = -0.440, P < 0.0001$ ). Out of all the baseline demographic factors, the child's age was a significant risk factor affecting the mother's QoL ( $P = 0.041$ ).

**Conclusion:** CP, being a debilitating disease, requires around-the-clock caregiving for the child. However, caregiving causes a significant impact on the QoL with increasing severity of depression among the mothers.

**Keywords:** Cerebral palsy, depression, primary caregiver, quality of life

## Introduction

Several parents want their children to be fit and healthy to cope up with the competitive world. However, if some physical or intellectual health issues develop in early childhood, parenting (caregiving) becomes stressful for most of them. Cerebral palsy (CP) is one of the most common childhood disorders with an incidence of 1.5–2 per 1,000 live births.<sup>[1,2]</sup> It is a disorder of the development of movement and posture, causing

activity limitations attributed to non-progressive disturbances of the foetal or infant brain that may also affect sensation, perception, cognition, communication and behaviour.<sup>[3,4]</sup>

In India, nearly 15–20% of the physically disabled children are affected by CP.<sup>[5]</sup> It is associated with an impaired motor function and has sensory, communicative and intellectual impairments, limiting self-care functions such as feeding, dressing, bathing and mobility.<sup>[3,4]</sup> These limitations can result in long-term and stressful parenting care that far exceed the children's everyday needs as they develop.<sup>[6,7]</sup>

The caregivers encounter the first stressful situation during the confirmation of the diagnosis, followed by coping with the caregiving demands, the treatment cost and dismantling

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the self-social life. The management of CP is based on a multidisciplinary team approach in which the parents, especially mothers, play a crucial role. In most cases, the provision of such care may prove detrimental to both the physical health and the psychological well-being of the parents (mother), along with an impact on the family income, family functioning and sibling adjustment.

In the past two decades, various researchers showed a significant effect of caregiving on mothers of children with CP than mothers of children without developmental disabilities and the general population.<sup>[8-12]</sup> The research also shows that the risk of developing depression is as much as 2.26 times in mothers of children with CP.<sup>[13]</sup>

Studies also show that the quality of life (QoL) in mothers of children with CP is affected negatively.<sup>[14-20]</sup> However, the results mainly describe the western data, where caregiving is a different aspect. Unlike the western culture, Indian mothers have an inherent caregiving nature, with most families being in joint family culture, leading to the care's diversion. Also, research shows conflicting evidence of the association of depression with the child's functional level in motor development.

Given this, the present study was conducted to determine the effects of primary caregiving for a child with CP on the primary caregiver's QoL in the Indian scenario. The results of the present study will hold relevance in guiding the caregivers of the patients to future generations.

## Methods

The present study was an observational cross-sectional study on 203 primary caregivers (mothers) of children with CP who visited the Out-Patient department from July 2015 to June 2016. The study was undertaken after ethical clearance at the All India Institute of Physical Medicine and Rehabilitation, Mumbai (IEC/AIIPMR/2015/03).

The study included the mothers of children with CP up to 18 years of age, who understood and completed the questionnaire. The diagnosis of CP in children was based on the clinical assessment. The mothers with any chronic medical condition or history of existing psychological disorder were excluded. Written informed consent was obtained from them before enrolling in the study.

The demographic details such as the child's age and gender, mother's education and annual family income were noted. After examining the child, the type of CP (spasticity, ataxia, dystonia, athetosis and mixed) and the child's motor function level were noted. The functional level was determined using the Gross Motor Functional Classification System- Expanded and Revised (GMFCS-ER), where the lower level indicates the child's better function. The outcome measures were the prevalence of depression among the mothers and the caregiving's effect on the WHOQOL-BREF scale domains on the child's motor function status.

The measurement tools were (1) the Montgomery–Asberg Depression Rating Scale, which consists of 10 questions; each scored between 0 and 6 with a total score of 60. The scores were rated as normal (0–6), mild depression (7–19), moderate depression (20–34) and severe depression (>34); (2) The WHOQOL-BREF Hindi version was used to assess the QoL of the mothers. The WHOQOL-BREF comprises four domains consisting of 24 questions.

## Statistical analysis

The presentation of the categorical variables was done in the form of numbers and percentages (%). On the other hand, the continuous variables' presentation was done as mean  $\pm$  SD and median values. The data normality was checked by using the Kolmogorov–Smirnov test. In the cases in which the data was not normal, we used nonparametric tests. The Spearman's rank correlation coefficient was used to correlate the QoL with GMFCS-ER grading and Montgomery–Asberg Depression Rating Scale. The univariate linear regression was used to find out factors affecting the total QoL. The final analysis was done with the use of the Statistical Package for Social Sciences (SPSS) software ver 21.0. For statistical significance, the *P* value of less than 0.05 was considered significant.

## Results

The mean age of the study children with CP was  $9.34 \pm 4.6$  years with 41.38% ( $n = 84$ ) females and 58.62% ( $n = 119$ ) males. Among the participants, 56.65% ( $n = 115$ ) of the mothers belonged to low-income group, i.e., below 1 lakh annual income with 6.4% ( $n = 13$ ) primary educated, 32.02% ( $n = 65$ ) secondary educated, 36.95% ( $n = 75$ ) graduate and 24.63% ( $n = 50$ ) post-graduate. Table 1 shows the demographic characteristics of the study population.

The type of CP was spastic in most children (57.14%), followed by dystonic type in 18.72%. The minor types included ataxic (1.97%), athetoid (3.94%) and mixed types (18.23%). The

**Table 1: Distribution of sociodemographic profile**

Sociodemographic parameters	Subcategories	Frequency	Percentage
Distribution of age of children	1-5 years	46	22.66%
	6-12 years	105	51.72%
	13-18 years	52	25.62%
	Mean $\pm$ SD	9.34 $\pm$ 4.6	
Gender distribution	Female	84	41.38%
	Male	119	58.62%
Family income (per annum in rupees)	<50,000	40	19.70%
	50 k to 1 lakh	75	36.95%
	1 lakh to 3 lakhs	67	33.00%
	>3 lakh	21	10.34%
Mother's education	Primary	13	6.40%
	Secondary	65	32.02%
	Graduate	75	36.95%
	Post-graduate	50	24.63%

GMFCS-ER grading showed that 9.36% of the children were in level 1, 18.23% were in level 2, 23.15% were in level 3, 26.11% were in level 4 and 23.15% were in level 5.

As per the Montgomery–Asberg Depression Rating Scale, the mothers’ mean depression score was  $22.97 \pm 14.57$ . It was found that 35 (17.24%) mothers had no depression, 63 (31.03%) had mild depression, 51 (25.12%) had moderate depression and 54 (26.6%) had severe depression.

As per the WHOQOL-BREF, the mean  $\pm$  SD score of the physical domain was  $69.81 \pm 13.02$ , the psychological domain was  $67.49 \pm 12.64$ , the social relationships was  $58.51 \pm 9.64$  and the environmental domain was  $60.49 \pm 9.67$ .

The association between the depression rating scales with the level of GMFCS-ER was significant. About 68.42% of the mothers of children with GMFCS-ER level 1 had no depression, whereas 65.96% of the mothers of children with GMFCS-ER level 5 had severe depression [Table 2].

The mean QoL domains scores showed a decreasing trend with increasing motor dysfunction of the child; however, a statistical association was achieved only for physical ( $r = -0.327, P < 0.0001$ ) and psychological domains ( $r = -0.440, P < 0.0001$ ) [Table 3 and Figures 1-4].

With the increasing severity of depression (normal, mild, moderate and severe), the QoL’s domains showed a significantly decreasing trend, as shown in Table 3. There was a significantly negative correlation of depression with the quality-of-life domains, affecting all aspects. The Montgomery–Asberg Depression Rating Scale showed a statistically significant negative correlation with physical domain ( $r = -0.498, P < 0.0001$ ), psychological domain ( $r = -0.486, P < 0.0001$ ), social relationships ( $r = -0.165,$

$P = 0.019$ ) and environmental domain ( $r = -0.195, P = 0.005$ ) as shown in Figures 5-8.

Out of all the baseline demographic factors, the child’s age was a significant risk factor affecting the mother’s QoL ( $P = 0.041$ ) [Table 4].

## Discussion

The earlier studies show depression in caregivers ranging from 30 to 61.2%, comparable with our study.<sup>[21-23]</sup> Ones *et al.*, Kaya *et al.*, Hamzat and Mordi, Manuel *et al.* found no significant correlation in the child’s motor function level with the mother’s depression.<sup>[11,23-25]</sup> Byrne *et al.*<sup>[25]</sup> found poor mental and physical health in CP caregivers compared to the average population;

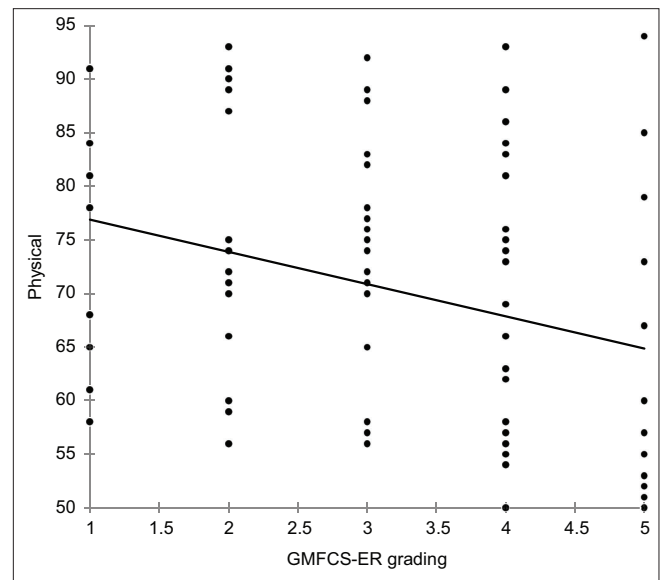


Figure 1: Correlation of GMFCS grading with physical

Table 2: Association of the Montgomery-Asberg scale with GMFCS-ER level

Montgomery-Asberg scale	GMFCS Level 1 (n=19)	GMFCS Level 2 (n=37)	GMFCS Level 3 (n=47)	GMFCS Level 4 (n=53)	GMFCS Level 5 (n=47)	P	Test Performed
Normal	13 (68.42%)	12 (32.43%)	8 (17.02%)	2 (3.77%)	0 (0%)	<.0001	Pearson’s Chi-square test=120.745
Mild	6 (31.58%)	15 (40.54%)	24 (51.06%)	16 (30.19%)	2 (4.26%)		
Moderate	0 (0%)	8 (21.62%)	13 (27.66%)	16 (30.19%)	14 (29.79%)		
Severe	0 (0%)	2 (5.41%)	2 (4.26%)	19 (35.85%)	31 (65.96%)		
Mean $\pm$ SD	7.26 $\pm$ 4.78	14.22 $\pm$ 10.44	17.36 $\pm$ 8.55	27.62 $\pm$ 14.73	36.57 $\pm$ 10.47	<.0001	Kruskal-Wallis test; Chi-square=90.564
Median (IQR)	5 (4.5-10)	11 (6-21)	17 (12-21)	26 (15-36)	38 (27.5-45)		
Range	3-16	3-39	4-35	6-51	13-51		

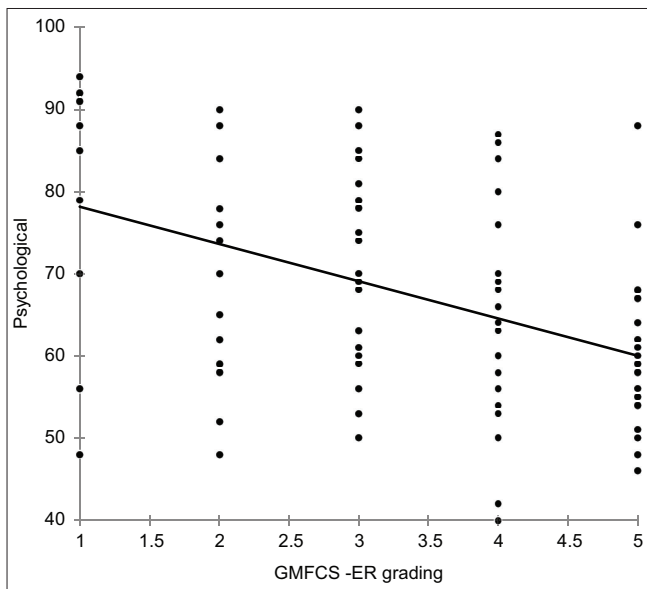
Table 3: Correlation of quality-of-life domains, depression in mothers and motor dysfunction in the child

Variables	Physical	Psychological	Social relationships	Environmental
GMFCS-ER grading				
Correlation coefficient	-0.327	-0.440	-0.006	-0.078
P	<0.0001	<0.0001	0.934	0.269
Montgomery-Asberg depression rating scale				
Correlation coefficient	-0.498	-0.486	-0.165	-0.195
P	<0.0001	<0.0001	0.019	0.005

Spearman’s rank correlation coefficient

**Table 4: Univariate linear regression to find out factors affecting the total quality of life**

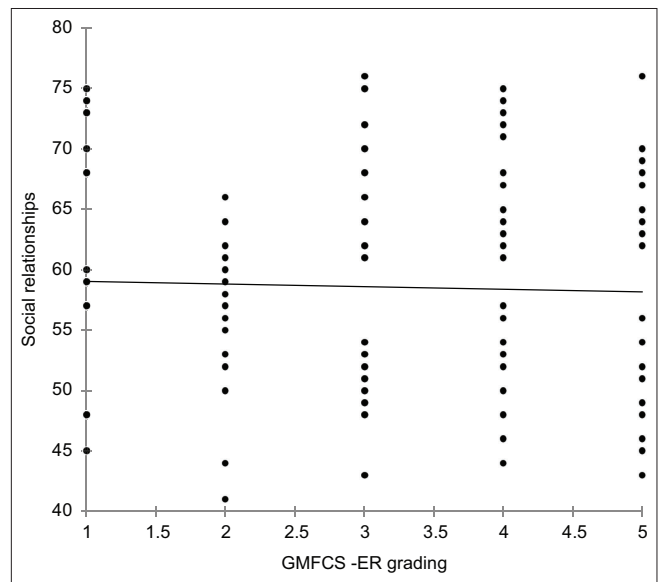
Variable	Beta coefficient	Standard error	P	Lower bound (95%)	Upper bound (95%)
Age (years)	0.211	0.103	0.041	0.009	0.414
Gender					
Male					
Female	-0.397	0.966	0.681	-2.302	1.508
Mother's education					
Primary					
Secondary	-2.147	1.317	0.105	-4.745	0.451
Graduation	-1.610	1.345	0.233	-4.261	1.042
Post-graduation	0.962	1.813	0.596	-2.614	4.538
Income (per annum)					
<50,000					
50 k to 1 lakh	-3.215	2.033	0.115	-7.225	0.794
1 lakh to 3 lakh	-0.365	2.011	0.856	-4.330	3.600
>3 lakh	-0.902	2.083	0.666	-5.010	3.207



**Figure 2:** Correlation of GMFCS grading with psychological

however, they found no relation of mental health with the functional level of CP child.<sup>[26]</sup> However, our study shows a significant association of depression with the functional level of CP children, consistent with the latest research.<sup>[1-4,27,28]</sup>

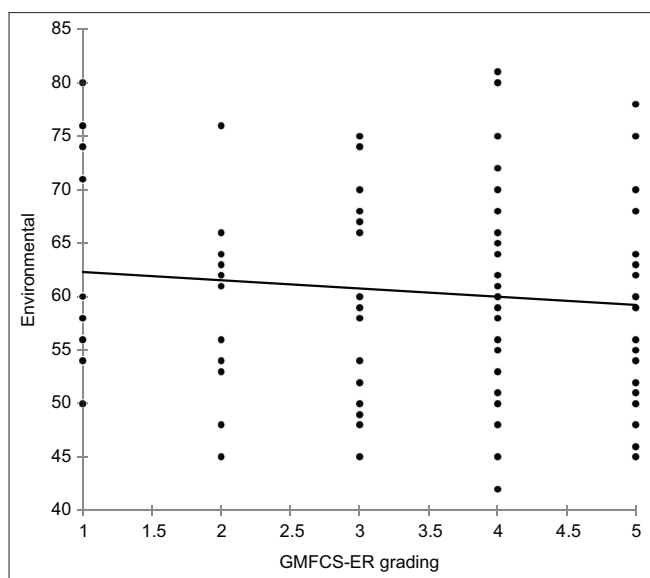
We found that the higher the functional limitation of the child higher was the depression level among the caregivers. The reason for significance in our setting could be because of the social beliefs rooted in the Indian society that mothers only are responsible for developing their children. An Indian study by Sardana R *et al.*<sup>[28]</sup> concluded that caregivers of children with CP experience disruption of family activities, leisure and interaction.<sup>[29]</sup> A feeling of guilt and self-accusation thoughts can lead to low self-esteem in this population. Low-income families and social support to the caregiver make them think of being isolated and outcast from society. In a developing country like India, delayed diagnosis and delayed rehabilitation measures add-on to the situation.



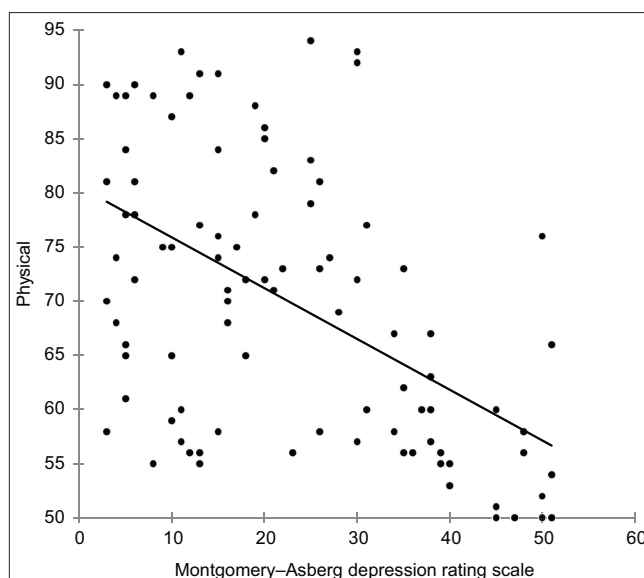
**Figure 3:** Correlation of GMFCS grading with social relationships

The QoL was also significantly affected by the functional level of the CP child, especially in physical and psychological domains. The social and environmental domains were not significantly associated. Our findings were consistent with the western studies and a few middle eastern studies where the QoL of caregivers was negatively affected by CP.<sup>[1-4,30,31]</sup> On comparing the QoL domains with the depression level, it was evident that all the domains are affected by depression suggesting that depression has a negative impact on the caregivers' QoL, no matter the reason for that depression.

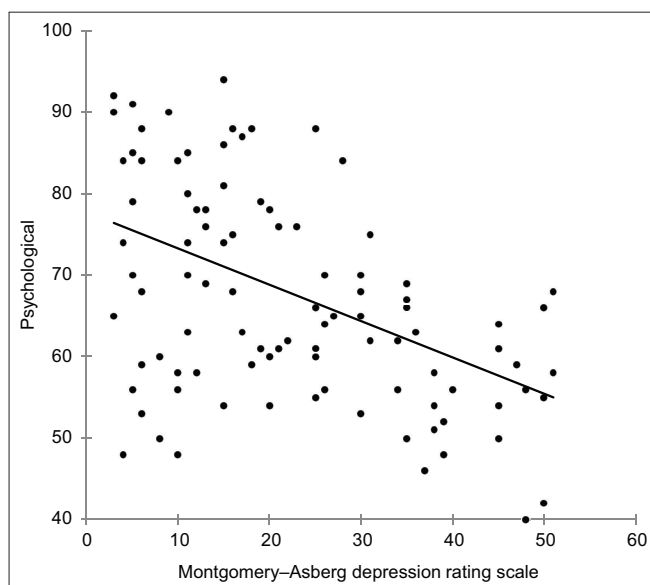
In our study, the age of the child was found as a significant risk factor affecting the QoL of the mother. A study by Obembe *et al.*<sup>[31]</sup> also shows that the age of the child has a great impact on the psychological state of the caregivers.<sup>[32]</sup> A Korean study on family functioning and the burden of parents with CP children shows a significant correlation of the age of the child with the caregiver's difficulty.<sup>[4]</sup> The reasons for such a finding could be due to various



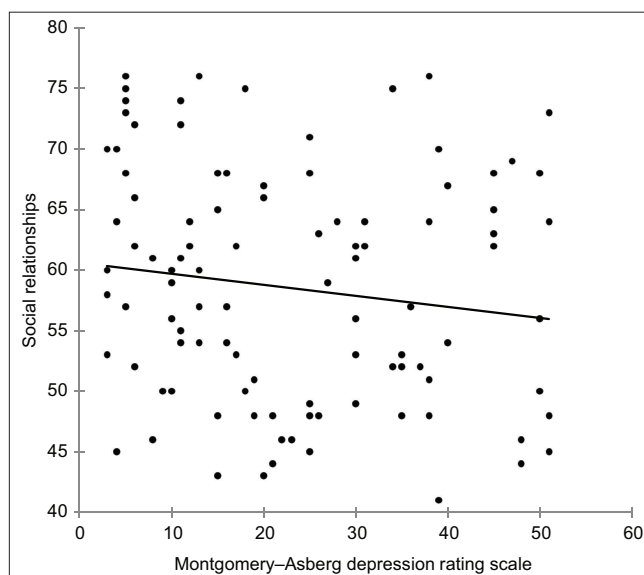
**Figure 4:** Correlation of GMFCS grading with environmental.



**Figure 5:** Correlation of Montgomery-Asberg Depression Rating Scale with physical



**Figure 6:** Correlation of Montgomery-Asberg Depression Rating Scale with psychological

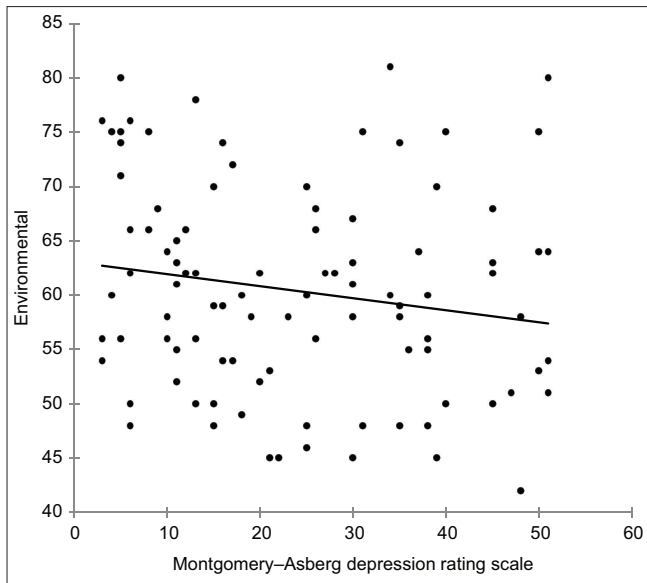


**Figure 7:** Correlation of Montgomery-Asberg Depression Rating Scale with social relationships

stressors in a caregiver’s life: Physical stressor of moving the child, cleaning the child increases as the child grows, emotional stressor concerning the future of the child and financial stressor to cater for the treatment of the child.<sup>[33]</sup> The number of children, the age of the child with cerebral palsy, the functional level of the child and the depression level of the child were independent risk factors in the musculoskeletal system pain of the mothers who had children with CP and who developed locomotor system pain.<sup>[33]</sup> But a study by Jamali A *et al.* shows independent variables like GMFCS, The Manual Ability Classification System (MACS), Eating and Drinking Ability Classification System (EDACS), Communication Function Classification System (CFCS), seizure, IQ, age, gender and the auditory and visual problem cannot predict a caregiver’s difficulty but it may correlate with these factors.<sup>[34]</sup>

The study provides a message to the primary care physician that the primary caregiver and the family should be counselled about taking care of a child with cerebral palsy. The study also tells that despite being a mother, primary caregiving can become hectic and lead to depression and decreased QoL. This aspect needs to be kept in mind while treating a child with CP so that overall, both the patient and the family members can recover from the disease.

The study’s limitation was that no control group was included for comparison; other associated disabilities like mental retardation, speech disturbance and hearing problems were not accounted for.



**Figure 8:** Correlation of Montgomery-Asberg Depression Rating Scale with environmental

The study had strengths since it assessed the child's and the mother's aspect of deranging child motor functions and the mother's affected mental health and QoL. It must be stressed here that though the caregiving of the child comes out of love, the extra care as required by the CP children may cause extra stress and burden on the mother, thereby, deteriorating her health, which in the long run, maybe detrimental to both the mother and the child. These may decrease the mother's love for the child or make the mother feel unwell, which may destroy the family environment, causing additional stress on the other family members. However, the long-term outcome of the decreased QoL needs to be explored in future studies since the present study was cross-sectional in design with no further follow-up of the patients.

## Conclusion

In an Indian setting, managing the CP syndrome at home-based care cannot be achieved without the caregiver's participation, which is often the child's mother. Depression is significantly associated with primary caregivers because of the increased perceived stress of caregiving. This also affects the mothers' QoL in increasing the proportion of depression with their children's functional impairment. Therefore, it is essential to consider the caregiver's mental status and provide multidisciplinary physical, psychological and social support to the mother, ensuring better rehabilitation outcomes for the child and the primary caregivers.

## Key points

- Though the mother is attached the most to the child, still taking care of a CP child can be a daunting task.
- Counselling for caretaking must be provided to the whole family for decreasing the mental and physical exertion on the primary caregiver.

- The family members must take note to improve the QoL of the primary caregiver by providing physical, social and psychological support.

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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## Conflicts of interest

There are no conflicts of interest.

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