

## Quality of life in mothers of children with cerebral palsy in a tertiary care hospital in Kolkata.

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### Abstract:

**Introduction:** Cerebral Palsy (CP) is one of the commonest developmental disorders of early childhood which persist throughout life. A child of CP has several care-needs and the quality of life (QOL) of the care-giver is an important determinant for the proper rehabilitation of the CP child. **Objective:** To compare the QOL between mothers of CP children and their age-matched controls and to examine relationship between QOL of mothers and certain socio-demographic variables. **Methodology:** It was an analytical, retrospective case control study with cross-sectional design. 100 cases of less than 12 years aged CP children attending CP clinic and OT department of National Institute of Orthopedically Handicapped (NIOH) and 100 matched controls from community were selected. WHOQOL-BREF Questionnaire was used to assess the QOL; Gross Motor Function Classification System (GMFCS) was used to assess the severity of child's movement disorder. Data were analyzed in Microsoft Excel workbook, descriptive statistics calculated as mean, SD, Chi-square & student's t-test were used to examine relevant statistical significance with  $p \leq 0.05$  as significance level. **Result:** The QOL of the mothers of children with CP is lower than that of the mothers of healthy children in all the four domains and difference is statistically significant. The difference is found to be significant ( $p < 0.05$ ) in all domains except for the social domain for nuclear and Muslim families. There is a declining trend in the QOL scores according to the socio-economic status I to V. **Conclusion:** The QOL of the mothers of children with CP is worse than that of the mothers of healthy children in all the four domains of QOL. Money seems to be an important determinant of the QOL as there is a declining trend in the QOL scores according to the socio-economic status from I to V. Probably, support system is an important determinant among the Muslim mothers and the nuclear families in determining their quality of life.

**Key words:** Quality of life, Mothers, Children with cerebral palsy, Kolkata.

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### I. Introduction

Cerebral palsy (CP) is a heterogeneous group of movement and posture disorders caused by non-progressive damage to the immature brain.<sup>1</sup> It may be accompanied by other disorders such as epilepsy, deficits in speech, hearing, vision and intellectual disability. It is one of the commonest developmental disorders that appears early in childhood and persists throughout life.

A cerebral palsy diagnosis brings with it a sense of unpredictability for the parents. The difficult and constant struggle to improve the child's health and development is accompanied by severe anxiety and often leads to feelings of helplessness and lack of control, and this in turn may contribute to feelings of parental incompetence. Brehaut et al. found that over the years, parents of children with cerebral palsy, compared with parents of healthy children, more frequently complain of experiencing severe and chronic stress, emotional and cognitive problems, as well as report numerous somatic complaints.<sup>2</sup>

According to the definition of the World Health Organization (WHO), quality of life means 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 aims, expectations, standards and interests, conditioned by the environment.<sup>3</sup> The basis of assessment of quality of life is to examine the state of the patient in the areas of physical, mental and social well-being as well as satisfaction with life in various domains.

Some studies found that, mothers of children with CP, compared to mothers of healthy children, more often have a poorer quality of life.<sup>1, 4, 5, 6</sup> Few studies identified factors which might affect QOL of mothers

of CP child. 7 – 10 However, it was seen that caring for a child with CP does not equally affect all the parents. The quality of life of the care-giver is an important determinant for the proper rehabilitation of the CP child. So it is necessary to analyze the factors predisposing a poor QOL in mothers of CP children in a particular population as a primary step to design interventions to improve the family's adaptation to improve the rehabilitation process of CP children.

## **II. Methodology**

It was an analytical, retrospective case control study, cross-sectional in design, conducted at Occupational Therapy (OT) and Physical Medicine and Rehabilitation (PMR) Department of the National Institute for the Orthopedically Handicapped (NIOH), Kolkata during July – September 2015 after taking ethical clearance.

100 mothers having a child aged less than 12 years with CP, attending the CP clinic of OT department of NIOH, living with the child, non-pregnant, not having chronic disorder which may markedly affect QOL, having no history of psychological disorders, and not using antidepressant and anxiolytic drugs, constituted the study group. 100 age matched mothers of healthy children aged less than 12 years age selected from electoral roll of nearby Rajarhat-Gopalpur Municipality. Informed consent was taken from all participant mothers.

A pre-designed and pre-tested data collection form was used to collect the relevant socio-demographic and economic details of the cases and controls along with the significant medical information of their children. The WHOQOL-BREF Questionnaire in vernacular was used to assess the quality of life in four domains - physical health, psychological, social relationships and environment.

The Gross Motor Function Classification System (GMFCS) was used to assess the severity of child's movement disorder. Functional status of the patient is classified as: LEVEL I – Walks without limitations; LEVEL II - Walks with limitations; LEVEL III – Walks using a hand-held mobility device; LEVEL IV - Self-mobility with limitations, may use powered mobility and LEVEL V - Transported in a manual wheelchair. Where this classification could not be applied, the Expanded and Revised version of the same classification was used.<sup>16</sup>

Data were compiled and analyzed in Microsoft Excel workbook in computer. Descriptive statistics findings were expressed as range, mean, SD; Chi-square and student's t-tests were used to test statistical significance at  $p \leq 0.05$  significance level.

## **III. Result**

100 mothers of children with cerebral palsy cases and another 100 mothers with normal, healthy children were taken as control using selection criteria. WHO QOL BREF Questionnaire was used to collect the information. Mean age of cases was  $27.72 \pm 11.40$  years, range 17 – 43 years; and that of control was  $31.04 \pm 9.79$  years, range: 20 – 43 years. 79% cases and 88% controls were Hindu, 21% cases and 12% controls were Muslim. 27% of the cases lived in nuclear family and 73% lived in joint families; while 48% of controls lived in nuclear families and 52% in joint families. 59% of cases and 71% of control mothers had single child. Occupation-wise, 93% and 89% mothers among case and control were home maker. Educational status of the cases range from middle school (36%) to post-graduation degrees (10%) while that in control ranges from middle school (3%) to post-graduation degrees (54%). According to BG Prasad Socio-economic scale<sup>17</sup> (2014) 77% cases belonged to the socio-economic class IV and V and 76% control group belonged to the class I and II. No significant difference ( $p > 0.05$ ) according to age, religion, no. of children in family and occupation were found, whereas difference were significant ( $p \leq 0.05$ ) in relation to type of family, occupation and socio-economic status among case and control group. (Table 1)

13% of cases and 14% of controls had a chronically ill family member other than the child of cerebral palsy and required constant care and attention.

In both case and control groups, 40% cerebral palsy children were female and 60% were male. The mean age for male children among cases was 4.69 years, SD 2.96, range: 0.83 – 12 years; while the mean age for female CP children was 3.44 years, SD 2.10, range 1.67 – 11.92 years. For the control group, the mean age of the male child was 2.18 years, SD 4.92, range, 0.67 – 8.75 years while the mean age of the female child was 6.00 years, SD 2.11, range 1.33 – 9.92 years. (Table 2)

The severity of child's movement disorders were assessed using Gross Motor Function Classification System (GMFCS). As per this scale 1% children was in level - I (walks without limitations), 15% in level – II (Walks with limitations), 27% in level – III (Walks using a hand-held mobility device), 23% in level – IV (self mobility with limitations, may use powered mobility) and 34% were in level – V (transported in a manual wheelchair). (Diagram – 1)

Mother of both the groups was assessed for physical, psychological, social, environmental and overall domain and the mean domain scores of the groups were compared using t-test. The differences were found significant ( $p < 0.05$ ) in all domains; which implies that quality of life of mothers of children with cerebral palsy were lower than that of mothers of normal children. (Table 3)

Difference in quality of life score among case and control mother group were examined in relation to family type and religion. The difference in QOL among the case and control were found significant ( $p \leq 0.05$ ) in all domains except for the social domain for nuclear families ( $p > 0.05$ ). (Table 4) The difference in QOL among case and control of different religion was found significant ( $p \leq 0.05$ ) in all domains except in social domain for Muslim families ( $p > 0.05$ ). (Table 5)

A declining trend was observed in QOL scores according to the socio-economic status I to V. It was mostly pronounced in the environmental domain (33.5 in Grade I to 23.14 in Grade V) and social domain (15 in Grade I to 11.44 in Grade V). (Table 6, Diagram 2)

#### **IV. Discussion**

Total 100 cases were recruited consecutively from the CP clinic of NIOH, Kolkata and 100 controls were selected randomly from the nearby Rajarhat-Gopalpur Municipality. Mean age of the case group was  $27.72 \pm 11.4$  years and that of control was  $31.04 \pm 9.76$  years. The mean Quality of life of cases in all four domains were found significantly lower than control mothers. The difference in QOL among the control and case is found significant in all domains except for the social domain for nuclear families. There has been a declining trend in the QOL scores according to the socio-economic status I to V. It is mostly pronounced in the environmental and social domain.

Quite a good number of studies were found to assess QOL of care giver of CP children. In the study conducted by Okurowska et al, showed that QOL of parents of CP were lower in all four domains than the parent of healthy children. Significant difference was seen in environment and psychological domain.<sup>1</sup> Study of Noemí G et al. found that the scores in the three indexes of QOL and the WHOQOL-BREF Mental Health index were low among parent of CP children as compared with community sample.<sup>4</sup> Sajedi F et al, showed that having a child with CP increases the risk of developing depression in mothers as much as 2.26 times (OR=2.26).<sup>7</sup> Manuel et al. found that 30% of mothers of CP children had symptoms of depression. The severity of the disability and the functional status of the child did not affect the occurrence of depression.<sup>9</sup> Several studies have also found to determine if caring for the CP child also affected the physical or general health of the caregivers. Dehghan L et al, assessed QOL in mothers according to the gross motor function levels and types of CP. The results indicated that mothers had significantly low QOL.<sup>6</sup> The study by Romeo DM et al, showed that parents of children with CP had lower scores in the physical health and psychological domains compared with the control group.<sup>13</sup> Hamzat TK et al, also reported that caring for children with cerebral palsy had a negative impact on the health of their caregivers in comparison to normal children.<sup>14</sup> Ones K et al, also reported a significantly worsened QOL among mothers of Children with CP compared to the mothers of healthy children.<sup>15</sup> In study of Halim Y et al, among mothers with CP children, a negative correlation was detected between Beck Depression Inventory (BDI) scores and all subscale scores of 36-Item Short-Form Health Survey. The study concluded that health related QOL (HRQoL) is impaired in CP children's mothers, and depression is a significant symptom.<sup>5</sup>

#### **V. CONCLUSION**

The present study showed significant difference in the overall QOL score as well as score in its four domains, namely- Physical Health, Psychological, Social Relationships and Environment. The mothers having CP children scored significantly less compared to their age matched controls except in the social relationship domains among the Muslim mothers and among those from nuclear families. So it can be assumed the importance of social support system was not an important determinant among the Muslim mothers and the nuclear families in determining their quality of life. But, the per capita income seemed to have an important bearing on the quality of life. We found in our study that in differing magnitude, all the scores of QOL were comparatively better among the higher socio-economic class compared to their lower. Such a trend was most predominant in the environmental and social domain.

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**Tables & Diagrams:**

**Table 1:** Socio-demographic characters of cases and controls.

Socio-demographic characters of mothers	Cases n=100	Controls n=100	X <sup>2</sup> , df, p value
<b>Age (in years)</b>			
≤25	40	12	X <sup>2</sup> = 0.000056, df = 3, p>0.05
26 – 30	31	40	
31 – 35	22	30	
≥ 36	07	18	
Mean±SD	27.72±11.40	31.04±9.76	
<b>Religion</b>			
Hinduism	79	88	X <sup>2</sup> =2.94, df = 1, p>0.05
Islam	21	12	
<b>Type of family</b>			
Nuclear	27	48	X <sup>2</sup> =9.41, df = 1, p≤0.05
Joint	73	52	
<b>Total no. of children in family</b>			
One	59	71	X <sup>2</sup> =3.72, df = 3, p>0.05
Two	35	26	
Three	5	2	
Four or more	1	1	
<b>Education of mother of mother (last class passed)</b>			
Middle school	36	3	X <sup>2</sup> =2.94, df = 1, p>0.05
Secondary	43	11	
Higher secondary	11	32	
Graduation & above	10	54	
<b>Occupation</b>			
Home maker	93	89	X <sup>2</sup> = 87.39, df = 3, p≤0.05
Employed	7	11	
<b>Socio-economic status (as per B G Prasad's Socio-economic scale, 2014)</b>			
<b>Class(Per capita income)</b>			
I (Rs.5571 & above)	2	36	X <sup>2</sup> =97.79, df =4, p≤0.05
II(Rs. 2786 – 5570)	8	40	
III(Rs.1671 – 2785)	13	11	
IV(Rs.836 – 1670)	34	10	
V(Rs. Below 836)	43	03	

**Table 2 :** Age and sex-wise distribution of cerebral palsy children.

Age (in years)	Cases		Controls	
	Male	Female	Male	Female
<4	40	23	21	09
4 to <8	17	13	36	23
8 to <12	03	04	03	08
Mean, SD	4.69, 2.96	3.44, 2.10	2.18, 4.92	6.00, 2.11
Total	60	40	60	40

**Table 3:** comparison of mean QOL score of different domains among case and control mothers.

Domain	Cases		Controls		t, p-value
	Mean Score	SD	Mean Score	SD	
Overall	6.705	1.47	7.58	1.13	t=4.75, p≤0.05
Physical	25.26	4.71	27.87	4.04	t=4.21, p≤0.05
Psychological	18.29	4.50	23.03	3.49	t=8.32, p≤0.05
Social	11.58	2.68	12.41	1.93	t=2.51, p≤0.05
Environmental	24.50	4.66	28.60	5.25	t=5.84, p≤0.05

**Table 4:** Comparison of the Overall QOL and Mean Domain score among the different Types of families among the cases and controls.

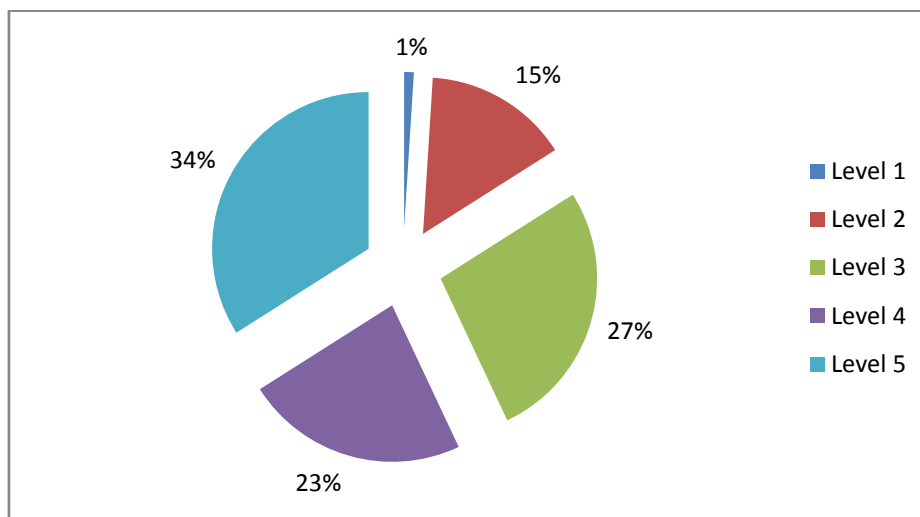
Type of family	Domain	Cases(Nuclear=27 , Joint=73 )		Controls(Nuclear=48, Joint=52)		t, p-value
		Mean Score	SD	Mean Score	SD	
Nuclear	Overall	6.72	1.53	7.44	0.92	t=2.55, p≤0.05
	Physical	25.37	4.08	27.58	3.64	t=2.42, p≤0.05
	Psychological	18.15	4.19	22.42	3.12	t=5.02, p≤0.05
	Social	11.71	2.83	12.25	1.80	t=1.01, p>0.5
	Environmental	24.68	4.87	28.21	4.73	t=3.07, p≤0.05
Joint	Overall	6.67	1.36	7.73	1.32	t=4.35, p≤0.05
	Physical	23.67	4.10	28.10	3.75	t=6.17, p≤0.05
	Psychological	18.67	4.40	23.63	3.23	t=7.47, p≤0.05
	Social	11.22	2.31	12.58	2.06	t=3.39, p≤0.05
	Environmental	24	4.15	29.02	5.72	t=5.82, p≤0.05

**Table5:** Comparison of the Mean Domains score of case and control among different Religion.

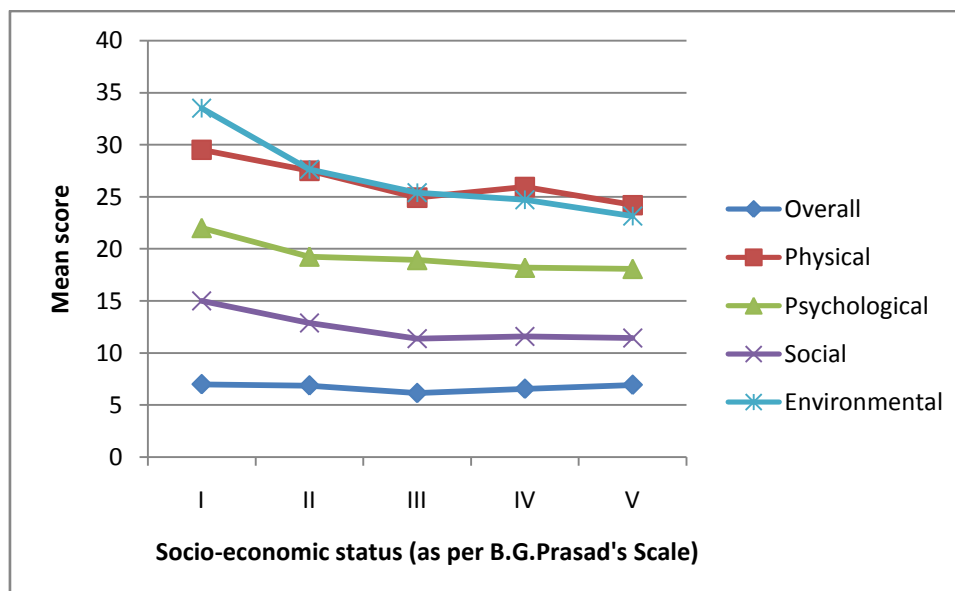
Religion	Domain	Cases (Hindu=79 Muslim=21)		Controls (Hindu=88 Muslim=12)		t, p-value
		Mean Score	SD	Mean Score	SD	
Hindu (H)	Overall	6.72	1.51	7.55	1.13	t=4.0468, p≤0.05
	Physical	25.18	3.88	27.88	3.74	t=4.5502, p≤0.05
	Psychological	18.35	3.94	22.94	3.21	t=8.2319, p≤0.05
	Social	11.80	2.44	12.48	1.86	t=2.0228, p≤0.05
	Environmental	24.34	4.41	28.45	5.30	t=5.3885, p≤0.05
Muslim (M)	Overall	6.67	1.35	7.83	1.11	t=2.6663, p≤0.05
	Physical	24.52	3.76	28.33	4.05	t=2.8483, p≤0.05
	Psychological	18.43	4.43	23.83	2.72	t=4.067, p≤0.05
	Social	10.76	3.43	11.92	2.39	t=1.0977, p>0.05
	Environmental	25.10	5.67	29.67	4.64	t=2.521, p≤0.05

**Table 6:** Mean Domain Score of the Cases according to B.G. Prasad's Socio Economic Scale.

Domain	Socio-economic status (B G Prasad Scale)									
	I		II		III		IV		V	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Overall	7	0	6.88	2.17	6.15	1.95	6.56	1.56	6.94	1.08
Physical	29.5	4.95	27.5	2.78	24.92	4.07	25.94	4.70	24.21	5.04
Psychological	22	9.90	19.25	5.39	18.92	3.52	18.18	4.85	18.07	4.11
Social	15	0	12.88	2.17	11.38	2.43	11.59	2.84	11.44	2.66
Environmental	33.5	0.71	27.63	4.07	25.38	5.12	24.71	4.29	23.14	4.27



**Diagram 1.** Distribution of the cerebral palsy children as per Gross Motor Function Classification System (GMFCS).



**Diagram 2:** Trend of mean scores of the overall quality of life & individual domains as per different grades of socio-economic status.

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