# Assessment of Quality of Life in Children with Cerebral Palsy

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#### Abstract

Introduction: Assessment of quality of life in children with Cerebral Palsy needs to be measure by CP- specific questionnaire.

**Objectives**: To assess quality of life in children with cerebralpalsy using CP specific questionnaire and tocorrelate the quality of life(QOL) with various demographic factors and clinical profile in these children.

Material & Methods: This study was a prospective and observational study and was conducted in department of Pediatrics at R.N.T. Medical College Udaipur and in various institutes. 102 patients of Cerebral Palsy between age of 2 to 18 years both male and female child, were included in the study and free from any other significant chronic illness.

Results: CP-QOL questionnaire was administered to 102 CP Children (81 male, 21Female). Majority of cases were Spastic diplegic (40.2%) followed by Paraplegic (21.6%). The mean score of CP Child is highest in age group 13-18 yr. Child score is more than parents score in each age group. The mean score by parents, child and total score is increases by education level of child with significant difference. There is no significant difference in mean score of child by education of parents. But total score is highest in higher education of parents. There is no significant difference in QOL by sex of child, socioeconomic status, location of residence and their perinatal history.

Conclusion: This study shows that many feasible changes can be adopted to improve the QOL of CP patients and their Parents.

Keywords: Parents, Cerebral Palsy and Quality of Life.

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#### I. Introduction

Cerebral palsy is a diagnostic term used to describe a group of permanent disorders of movement and posture causing activity limitation that are attributed to non-progressive disturbances in the developing fetal or infant brain. <sup>1,2,3</sup>

CP is the most common and costlyform of chronic motor disability that begins in childhood, and recent data from the Centers for Disease Control and Prevention indicate that the incidence is 3.6/1000with a male/female ratio of 1.4/1. In 80% of cases, features were identified pointing to antenatal factors causing abnormal brain development.  $^{1,4}$ 

CP is more common and more severe in boys compared to girls and this effect is enhanced at the extremes of body weight. 1

Multiple pregnancy was also associated with a higher incidence of CP and 12% of the cases in the European CP study resulted from a multiple pregnancy.<sup>1</sup>

Ignorance about the problem often causes more problems for a person with C.P. than the condition itself. Actually a child with C.P. is not hopeless. Half the children with C.P. have average or above average I.Q. with timely help and proper guidance a vast majority can lead active, self supporting and long lives. <sup>8</sup>

Quality of life measurement in children with cerebral palsy is important for deciding the need and effect of various interventions in management of cerebral palsy.<sup>9</sup>

#### II. Aims And Objectives

- 1. To assess quality of life in children with cerebralpalsy using CP specific questionnaire.
- 2. To correlate the quality of life with various demographic factors and clinical profile in these children.
- 3. To suggest methods for improvement in the areas where quality of life is poor.

#### III. Material And Methods

- 1. This study was a prospective and observational study and was conducted in department of Pediatrics at R.N.T. Medical College Udaipur and in various institutes.
- 2. Target population and study setting:
- 3. **Case:** Cerebral palsy patients (Boys and Girls) between 2 to 18 years of age, those were admitted to BalChikitsalaya, RNT Medical College, Narayan SevaSansthan Udaipur and Prayas school.

## 4. INCLUSION CRITERIA:

- 1. Clinically diagnosed cases of cerebral palsy.
- 2. Age between 2 to 18 years.
- 3. Both sexes.
- 4. Free from any other significant chronic illness.

#### 5. EXCLUSION CRITERIA:

- 1. Refusal for consent
- 2. Patients of age group less than 2 year and more than 18 years.

After fulfill inclusion criteria patients are broadly divided in four age group. Total 102 patients examined.

- (1) 2 -4 year (2) 5-8 year
- (3) 9-12 year (4) 13-18 year

#### METHOD OF COLLECTION OF DATA:

- 1. We collected social and biographical data.
- 2. We completed questionnaire sheet by Peds QL module. The Peds QL Measurement Model is a modular approach to measure health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions.

This form includes:

- 1. The Parent Report for Toddlers (Below 5 year)
- 2. The Child and Parent Reports (ages 5-18 year)

# Scoring system for assessment of the quality of life (Varni et al., 1998):

The Peds QLTM 3.0 Cerebral Palsy Module is comprised of parallel child self-report and parent proxy-report formats. Child self-report includes ages, 5-18 years. Parent proxy-report includes ages, 2-18 (child), and assesses parent's perceptions of their child's HRQOL. The instructions ask how much of a problem each item has been during the past 1 month.

- 0 = I never have a problem 1 = I almost never have a problem
- 2 = I sometimes have a problem 3 = I often have a problem
- 4 = I almost always have a problem.

# **Statistical Analysis:**

Statistical analysis was performed using SPSS Version 16.0.All quantitative results were reported as mean or mean  $\pm$  standard deviation.Independent sample t-testANOVA test was also used for find out significant difference for mean parents score ,mean child score ,and mean total score (mean of the parents and child) of quality of life and various demographic factors, cerebral palsy type, GMFCS, complications, mental retardation and physiotherapy.All the data were compiled and were subjected to analysis. P value was taken significant <0.05.

IV. Observations

Table-1: Age wise distribution of cerebral palsy children

Age		Sex			
		Male	Female	Total	
	Count	14	5	19	
	2-4 yr	% of Total	13.7%	4.9%	18.6%
	5-7 yr	Count	24	6	30
		% of Total	23.5%	6.9%	30.4%
8-12 yr 13-18 yr	0.13	Count	23	8	31
	8-12 уг	% of Total	22.5%	6.9%	29.4%
	12.10	Count	20	2	22
	% of Total	19.6%	2.0%	21.6%	

Total	Count	81	21	102
Total	% of Total	79.4%	20.6%	100.0%

Table 1 shows there was 102 CP children out of whom 81 (79.4%) were male and 21 (20.6%) were female.

Male to female ratio was almost 4:1. There were maximum 24 males in age-group 5 to 7 years and maximum number of females(6) in age group 8 to 12 years.

Table-2: The Number of Patients in various type of C.P.

	CP Type	No. of Patients	%	
0.Spastic Monoplegia		2	1.9	
1.	Spastic Paraplegia	22	21.6	
2.	Spastic triplegia	15	14.8	
3.	Spastic Diplegia	41	40.2	
4.	Spastic Quadriplegia	13	12.8	
5.	Spastic Hemiplegia	4	3.9	
6.	Dystonic	4	3.9	
7.	Mixed	1	0.9	

Table shows majority of cases were Spastic diplegic (40.2%)Followed by Paraplegic (21.6%).

Table-3: Mean score of CP child in Different age group

Age	Score p	Score c	Score
2-4 yr	61.32±1.43	-	-
5-8 yr	56.88±1.62	70.00±1.12	76.22±1.45
9-12 yr	65.15±1.65	71.21±1.64	75.22±1.74
13-18 yr	72.29±1.41	78.95±1.45	83.57±1.36
Total	63.82±1.60	72.88±1.47	77.86±1.50
P	0.008	0.084	0.138

Table shows that score is highest in age group 13-18 yr.Child score is more than parents score in each age group.

Table-4: Quality of life score in CP child according to Economic status

Eco.St	Score P	Score C	Score
Lower Lower	67.37±0.82	77.49±0.142	77.02±0.76
Upper Lower	66.45±1.46	73.08±1.33	77.34±1.34
Lower Middle	61.14±1.74	68.14±1.84	73.84±2.00
Upper Middle	59.83±2.00	76.10±1.25	79.84±1.44
Upper	70.59±1.62	79.95±.83	83.55±1.12
P	0.462	0.373	0.462

Table shows there is no significant difference in score of different economic status

Table-5:Mean score of child according to education level

Education of child	Score p	Score c	Score
Illiterate	49.41±1.42	60.64±1.53	67.65±1.85
Primary	70.96±1.14	77.87±.95	81.71±1.12
Middle	74.13±1.28	81.73±1.34	86.57±.96
Highschool	81.72±.06	85.85±.07	89.80±.81
P	0.000	0.000	0.000

Table shows mean score by parents, child and total score is increases by education level of child with significant difference.

Table-6: The Mean score of CP child according to education level of parents

Education of Parents	Score P	Score C	Score
Illiterate	71.87±1.22	77.55±1.23	79.92±1.32
Primary	64.40±2.10	72.52±2.00	77.33±1.45
Middle	63.54±1.44	71.83±1.55	79.34±1.83
High School	69.24±1.32	75.45±1.62	80.43±1.81
Graduate	61.30±1.45	71.01±1.25	75.65±1.46

Postgraduate	52.90±2.46	71.48±1.46	82.16±1.00
P	0.127	0.911	0.913

Table shows thatthere is no significant difference in mean score of child by education of parents. But total score is highest in higher education of parents.

Table-7: The mean score of CP child compared to antenatal history

ANH	Score P	Score c	Score
Not Significant	63.68±1.66	72.97±1.41	78.25±1.51
Preclampsia	57.17±1.24	58.73±1.32	59.36±2.00
Oligohydramnios	28.39±0.22	-	-
Bleeding	81.58±.95	83.47±.87	83.40±1.33
Fever	73.11±0.35	90.33±0.55	95.16±0.34
Decrease Foetal Movement	66.20±1.34	79.66±1.24	81.55±.78
IDM	61.66±0.87	71.11±0.36	85.55±0.46
Multiple	72.81±0.66	79.70±0.42	89.85±0.52
P	0.211	0.251	0.126

#### V. Discussion

Table no.1 shows number and percentage distribution of cerebral palsypatients according to age and sex. There were 102 CP children, out of which 81 (79.4%) were male and 21 (20.6%) were female. Male to female ratio was almost 4:1. These may be because the parents pay more attention to male offsprings in comparison to females and brought more of them to institute. There were maximum 24 males in age-group 5 to 7 years and maximum number of females (6) in age group 8 to 12 years. The number of patients in age group 9-12 were 31, in age group 5-7 yr 30, in 13-18 yr were 19 and in 2-4 yr were 19. The mean age of CP children in this study is 8.62 years.

Table no.2 shows the distribution of patients according to type of cerebral palsy. In this study maximum number of patients were of spastic diplegic type 41(40.2 %) followed by paraplegia 22 (21.6%). The number of patients in spastic quadriplegic group were 13 (12.8), spastic triplegic were 13 (14.8), spastic hemiplegia 4(3.9%), dystonic 4(3.9%), Spastimonoplegic 2(1.9%) and mixed 1(.9%).

In table no. 3 we observed that mean score of quality of life in different age groups increases with age. The maximum score according to parents and child were in age group 4 (13-18 yr). The difference was significant between age group 2(5-8 yr) and 4 (13 to 18 yr). These findings were in accordance with Anju Aggarwal et al that quality of life varied significantly with age. In Their study quality of life questionnaire (parent proxy version) for children 4-12 years was administered to parents of 50 children with cerebral palsy. Questionnaire was scored as per instruction and required statistical analysis was carried out.

According to table no.4there was no significant difference of quality of life score of child by different socioeconomic status. Although score increased with increase in economic status of family. These findings matched with AdegokeBabatunde O. A. et al who found in their study that caring for a child with cp significantly impacted on the QOL and health of the mothers, irrespective of their socio-economic status.

Table no. 5 shows that mean score by parents, child and total score increases by education level of child with significant difference. It may probably be, due to increase in awareness of self care and understanding their problems and communication with increasing educational status.

Table no.6 showsthat there is no significant difference in mean score of child by education of parents, but total score is increase in higher education of parents. These finding is in accordance with AnjuAggarwal et al who found that Quality of life varied significantly with age and maternal education (P<0.05).

Table no. 7 showed the mean score of child QOL compared with their antenatal history .we found that there is no significant difference in qol by their antenatal history.

In comparison to age the mean score was least in 2-4 yr group and it varied significantly from other group (5-18 yr). In regard toGMFCS, the entertainment score is less in GMFCS 5 group. As we analysethe score with different types of CP we observed that it was lowest in spastic quadriplegic type. As regards the relationship of entertainment activity with mental retardation, in CP children the QOL score of entertainment activity was lowest in children having severe degree of mental retardation.

## **VI. Summary And Conclusions**

To summarize our observation

a. We observed that mean score of quality of life in different age groups increased with age. The maximum score was in age group 13-18 yr, which was significant.

- b. The mean score as assessed by parents, child and total score increased as the education level of child and parents increased. It may probably be, due to increase in awareness of self-care and understanding their problems and communication with increasing educational status.
- c. We found that there was significant difference in mean score in different type of cerebral palsy. Highest score in spastic monoplegic type (81.93+-0.64), and lowest score in mixed type (36.32+-1.88) of CP.
- d. The mean score of QOL decreased with decreasing mobility.QOL was maximum in grade 1(83.02+-.56), and was minimum in grade 5(23.16+-1.28).
- e. The QOL score was maximum in CP children without complications (68.53+-1.33)in comparison to CP children with complications(52.33+-2.45).
- f. The mean score was compared with severity of mental retardation in CP children. It was maximum in CP child without mental retardation (82.08+-0.94) and minimum in CP child with severe mental retardation (45.12+-1.3).
- g. The mean score of QOL was significantly more in those children who regularly received physiotherapy (67.41+-1.62)in comparison to those who did not receive regular physiotherapy(62.85+-1.94).
- h. We did not find any significant correlation between the QOL score and sex of the child, socioeconomic status, location of residence and perinatal history.

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