



## QUALITY OF LIFE AMONG THE PARENTS OF CHILDREN WITH CEREBRAL PALSY

### KEYWORDS

Children, Cerebral Palsy, parents, Quality of life.

**R. Sridhar**

Ph.D Scholar, Dept. of Social Work, Bharathidasan University, Trichy

**Dr. D Nirmala**

Assistant Professor, Dept. of Social Work, Bharathidasan University, Trichy

### ABSTRACT

According to WHO (1993) Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. Cerebral palsy is a group of permanent disorder which occur in early childhood. Present study on "Quality of life among the parents of children with cerebral palsy" was conducted with the objectives of studying the socio-demographic characters, economic status and the quality of life experienced by parents of individuals with cerebral palsy. The study was conducted in a special school at Tiruchirappalli. A sample of 37 parents of children with cerebral palsy was selected out of 82 by purposive sampling method using descriptive design. Quality of life scale by World Health Organization was applied to draw out the necessary data. It was found that the mean age of the respondents was 32.92; most of the respondents family income was very low; more than three fourth of the respondents (78%) possess low level of quality of life. suitable suggestions were made to improve their quality of life.

### Introduction

Living a quality and peaceful life is each and every individual's desire and right too. If the life is built with joy, love and peace among family members, friends, neighbours and society, they are gifted. One way or the other if the quality gets affected in life, they are forced to live a compromising life. WHO, in its Quality of Life Assessment, determine four main factors as indicators of quality of life for an individual. They are Physical, Psychological, Social relationship and Environmental domains. Now-a-days, most of the common people deficit in any of the factors and tend to live a lower quality of life. When the concept is perceived from parent of a child with Cerebral Palsy, it affects them all the way. Parenting a child with Cerebral Palsy affect parent's daily routine life (Bumin.G 2008). Their health, wealth and social interaction and participation in community activities are lacking. So, a study was made to assess the level of the quality of life among the parents of children with Cerebral Palsy.

### Methods & Materials

The study was done based on the following objectives: To study the socio demographic characters, economic status, and to measure the quality of life experienced by the respondents. The study is descriptive in nature. The study was conducted at a Special school at Tiruchirappalli. The universe consists of 82 parents of children with disabilities. By adopting purposive sampling methodology, 37 parents of children with Cerebral Palsy were selected for the study. The interview schedule was used to collect socio demographic characters, the functional level of children were assessed by Gross Motor Functional Classification System (GMFCS) and the QoL-BREF by WHO (2004) was used to measure the Quality of Life. The reliability value of the scale is Cronbach's Alpha .983. The following hypotheses were framed by the researcher. a) There's association between age of the respondents and their quality of life; b) There's association between family income and their quality of life; c) There is association between birth order of the child and their parents' Quality of life; d) There's difference among the functional level of the child and their parents' quality of life; e) There's difference among the educational qualification of the respondents and their quality of life. To analyze the hypotheses,

statistical tests like chi-square test and ANOVA test was applied.

### Results & Discussion

#### Socio-Demographic characteristics of the respondents:

The mean age of mothers were 32.92. More than half (59.5%) of the respondents belonged to the age group of 31~40 years. A Vast majority (94.6%) of the respondents were mothers of the children while remaining were fathers. More than half (54.1%) of the respondents have studied upto 10th standard while more than one fourth(27%) were illiterate. More than half of the respondents (56.8%) residing at urban area. Nearly Three fourth (70.3%) of the respondents' type of marriage was non Consanguineous; living as nuclear family. More than one third (35.1%) of the respondents' spouse were employed in private concerns. Less than three fourth (70.3%) of the respondent's monthly family income were upto Rupees Five Thousand. Three fourth (75.7%) of the respondents felt that the low level of income is a barrier to bring up the child with Cerebral Palsy. More than half (54.1%) of the respondents were affected by child's gender as male. Nearly Three fourth (73%) respondents' children were first born. More than one third (40.5%) of the respondents' child belonged to the age group of 6 ~10 years. Regarding their opinion on future physical fitness to care the child was found satisfied to some extent among more than half of (67.6%) of the respondents.]

**Table no. 1**  
**DISTRIBUTION OF RESPONDENTS BY THEIR LEVEL OF QUALITY OF LIFE**

S.No	Quality of Life	No of Respondents (n:37)	Percentage
1.	Overall		
	Low level	29	78.4
	High level	8	21.6

above table depicts that more than three fourth of the respondents possess low level and one fifth of the respondents pos-

sess high level of quality of life. A study made by Davis et.al (2010) supports the findings. Parents of children with Pervasive Development Disorder (PDDs), Cerebral Palsy (CP) or Mental Retardation (MR) possess lower level of quality of life when compared with typically grown children. (Mugno et al, 2007). Families having a child with disability undergo psychological stress, anxiety and depression which lead to some other diseases such as pain and discomfort which dramatically diminish the quality of life of mothers. (Borzoo, S., Nickbakht, M., & Jalalian, M. 2014).

**Table no. 2**  
**Association between the age and quality of life experienced by the respondents**

Sl. No.	AGE	Level of QOL		Statistical inference
		Low	High	
1.	21-30	11	4	$\chi^2 = 3.779$ df=2 P>0.05 Not Significant
2.	31-40	18	4	

Chi-square test was applied to find out the association between age and the quality of life experienced by the respondents.

The result shows that the calculated value (3.779) is less than the table value at 5% level of significance. Since the calculated value is less than the table value it is inferred that there is no significant association between age and the Quality of life experienced by the respondents. Hence the null hypothesis is accepted. Weakening of Mental Health in mothers of children with cerebral palsy may be causing more Lower Back Pain; increased Lower Back Pain lead path to deterioration of health-related Quality of life.(Kurtulus Kaya et al 2010)

**Table no. 3**  
**Association between family income and quality of life experienced by the respondents**

Sl. No.	Income	Level of QOL		Statistical inference
		Low	High	
1.	upto 5000	22	5	$\chi^2 = 11.865$ df = 2 P0.05 Significant
2.	5001-10000	7	3	

Chi-square test was applied to find out the association between the birth order of the child and quality of life experienced by the respondents. The result shows that the calculated value (6.512) is more than the table value at 5% level of significance. Since the calculated value is more than the table value it is inferred that there is a significant association between birth order of child and quality of life experienced by the respondents. Hence the null hypothesis is rejected.

**Table No. 5**  
**One way analysis of variance among the Functional level of the child With regard to their parents' Quality of Life**

Sl. No.	Function al Level	Mean	SS	MS	df	Statistical inference
1	Between	G1 = 76.00	5973.396	1493.349	4	f=.007 p0.05 significant
		G2 = 63.75				
		G3 = 53.82				
		G4 = 41.67				
		G5 = 40.77				

- G1 = GMFCS Level I- walks without limitations
- G2 = GMFCS Level II-walks with limitations
- G3 = GMFCS Level III- walks with adaptive equipment assistance.
- G4 = GMFCS Level IV- self-mobility with use of powered mobility assistance.
- G5 = GMFCS Level V- severe head and trunk control limitations.

One way analysis of variance was applied to find out the difference among the functional level of the child and quality of life experienced by the respondents. The calculated value (4.241) is greater than the table value at 5% level of significance. Since the calculated value is greater than the table value it is inferred that there is a significant difference among the functional level of the child and quality of life experienced by the respondents. Hence the null hypothesis is rejected. It means the functional level of the child has very much influence on the respondents' quality of life.

The mean score reveals that the quality of life is high among the parents of children who can walk without limitations. Among the parents of children with severe head and trunk control limitations (GMFCS V), the quality of life is very low when compared with parents of children with GMFCS I.

It is evident that higher the functional level of the child, higher the quality of life of parents. A study by Shelley, A. et al (2008) conclude that the functional level of the child impact the parents' quality of life. The parents of child with Cerebral Palsy experience difficult periods throughout their lives. In the transition period of childhood to adolescent, they felt more difficult to treat. This period is often related with behaviour disorder which is a significant factor of parenting stress and worsens the quality of life (Mouilly, M et al 2014).

**Table No. 6**  
**One way analysis of variance among the educational qualification of the respondents with regard to their Quality of Life**

Sl. No.	Education Qualificatio n	Mean	SS	MS	df	Statistical inference
1	Between Groups	G1= 39.50	4222.373	1407.458	3	f=3.568 p0.05 Significant
		G2= 54.35				
		G3= 94.00				
	Within Groups		13018.383	394.496	33	

G1 = Illiterate G2= Upto 10th standard G3 = Higher Secondary G4= Graduation

One way analysis of variance was applied to find out the difference among the educational qualification and quality of life experienced by the respondents. The calculated value (3.568) is greater than the table value at 5% level of significance. Since the calculated value is greater than the table value it is inferred that there is a significant difference among the educational qualification and quality of life experienced by the respondents. Hence the null hypothesis is rejected. It means the educational qualification has very much influence on the quality of life. G.King, S.King, Rosenbaum and Goffin (1999) found that higher education qualification of parents was associated with fewer behaviour problems and decreased burden which leads to quality of life.

**Major findings**

It is inferred that more than three fourth of the parents possess low level of quality of life who care the child with cerebral palsy.

The dimension such as physical health, psychological aspects of their life, social relationship and environmental factors which influence their daily life seems low level. Birth order of the child has impact on quality of life of parents. Disability found on first child lowers the quality of life than the second child with disability. This aspect was studied by fewer authors; this is one of the gaps in the literature. Family's monthly income, education status of parents' and functional level of the child with cerebral palsy are some of the factors which impact the quality of life of parents having a child with cerebral palsy.

Caregivers pay less attention in their own health aspects. They experience irregular sleep, imbalanced food habits, failing to take regular medicine, not attending exercise; results in isolating themselves from social activities, clinical depression, high level of stress and low quality of life; if the caregiver is exhausted, depressed and experience low resilience, leads to low social interaction which causes decline in quality of life (Talley & Crews, 2007).

### Social Work Intervention

The quality of life is lower with three fourth of the respondents. In order to enhance the overall quality of life, classes may be arranged on teaching physical exercises for the parents may help them to overcome the physical issues arises by caring the child.

- Full time Social workers / counsellors have to be appointed in special schools to ventilate the parents' psychological issues then and there.
- Motivation class for parents helps to reduce their burden and issues.
- Parents may be encouraged to ventilate their psychological issues to the counsellor whenever they experience struggles and pain.
- Economic status impact the quality of life of parents of children with cerebral palsy. In order to increase the economic status:
- Income generation programme may be conducted for them. Some cottage industry work training may be provided for them.
- Intervention on short term target to increase the functional level of child would reduce the burden of the parents. Further it leads the child to function well in his/her daily activities.
- Among the illiterate parents, quality of life is very low. They may be given more awareness on cerebral palsy, condition of their child, and training on coping strategies may help them to overcome the issue.
- Empowering the parents to participate in social functions and family functions to strengthen their social relationship in the society.

### Conclusion

Parenting a child with cerebral palsy needs an ocean of patience, talent, courage and energy. When they lack in any of the aspect, the process becomes challenge for them. Parents need respite care which may be assisted by family members. Both the parents have to be boost up periodically to rear a quality child; thus the parenting talent also will be improved.

### REFERENCE

1. Bumin G, Günel A, Tükel B. Anxiety, depression and quality of life in mothers of disabled children. *S.D.Ü. Týp Fak Derg* 2008; 15(1): 6-11. | 2. Borzoo, S., Nickbakht, M., & Jalalian, M. (2014). Effect of Child's Cerebral Palsy on the Mother: a Case Control Study in Ahvaz, Iran, 31(1), 75-79. doi:10.2478/afmna-2014-0008 | 3. Davis E, Shelly A, Waters E, Boyd R, Cook K, Davern M, et al. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health Develop* 2010; 36(1): 63-73. <http://dx.doi.org/10.1111/j.1365-2214.2009.00989.x> | 4. G.King, S.King, Rosenbaum and Goffin (1999) Family centered caregiving and well-Being of parents of children with Disabilities: Linking process with outcome, *Journal of Pediatric Psychology*, Vol. 24, No. 1, 1999, pp. 41-53. | 5. Jill Wippermann (2013) The Quality of Life of Families of Children with Cerebral Palsy. Pp.21. | 6. Kurtulus Kaya et al (2010) Musculo-skeletal pain, quality of life and depression in mothers of children with cerebral palsy, Vol. 32, No. 20, Pages 1666-1672 (doi:10.3109/09638281003649912) | 7. Lawal, H., Anyebe, E. E., Obiako, O. R., & Garba, S. N. (2014). Socio-economic challenges of parents of children with neurological disorders: A hospital-based study in North West Nigeria, 6(August), 58-66. doi:10.5897/IJNM2014.0122 | 8. Mugno, D., Ruta, L., Arrigo, V. G. D., & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder, 9, 1-9. doi:10.1186/1477-7525-5-22 | 9. Mouilly, M., Faiz, N., Omar, A., & Ahami, T. (2014). The quality of life of parents with children and adolescents suffering from cerebral palsy, 9(4), 1700-1707. | 10. Shelley, A. et al. (2008). The relationship between quality of life and functioning for children with cerebral palsy, 199-203. doi:10.1111/j.1469-8749.2008.02031.x | 11. Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health*, 97(2), 224-228. | 12. World Health Organization. *Measuring Quality of Life* 1993.