International Journal of Health Sciences and Research
[Indexed, Peer-Reviewed Journal]
Volume 15; Issue: 8; August 2025
Website: www.ijhsr.org
Original Research Article *ISSN: 2249-9571*

Quality of Life of Mothers of Children with Cerebral Palsy Attending in a Tertiary Care Hospital in Eastern UP

Mohd Ghalib Khan[1], Tej Bali Singh[2], Rajniti Prasad[3]

[1]Research Scholar, Centre of Biostatistics, Institute of Medical Sciences, Varanasi
[2]Former Professor, Centre of Biostatistics, Institute of Medical Sciences, Varanasi,
[3]Professor, Department of Pediatrics, Institute of Medical Sciences, Banaras Hindu University, Varanasi.

Corresponding Author: Mohd Ghalib Khan

DOI: https://doi.org/10.52403/ijhsr.20250801

ABSTRACT

Background: Cerebral Palsy is a group of permanent disorders of movement and posture, associated with activity restriction, resulting from non-progressive disturbances that occurred in the developing fetal or infant brain. CP child has a range of care needs, the quality of life (QOL) of the caregiver plays an important role in deciding the successful rehabilitation of the child. The study aims to compare the QOL between of mothers of CP children and normal children and to examine relationship between QOL of mothers and certain socio-demographic variables.
Methodology: It was an hospital based case control study design. 125 cases of 2 to 18 years aged CP children attending pediatrics neurology unit and 125 controls from OPD, department of pediatrics were selected. WHOQOL-BREF Questionnaire was used to assess the QOL: Data were entered and analyzed using SPSS software version 28.0. Descriptive statistics findings were expressed as range, mean, SD; Chi-square and student's t-tests 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 mothers of normal children in all the four domains and difference is statistically different. The difference is found to be significant ($p<0.05$) in all domains both families expect for the social domain in nuclear family.
Conclusion: The QOL of the mothers of children with CP is worse than that of the mothers of normal children in all four domains of QOL.

Keywords: Cerebral Palsy, Quality of life, Mothers.

INTRODUCTION

The term cerebral palsy (CP) is a group of permanent disorders of movement and posture, associated with activity restriction, resulting from non-progressive disturbances that occurred in the developing fetal or infant brain. Motor disorders of CP are typically associated with disturbances of sensation, perception, cognition, communication and behavior, epilepsy, or secondary musculoskeletal issues [1]. The worldwide prevalence of cerebral palsy (CP) ranges from 1.5 to more than 4 per 1000 live births or per 1000 children in a particular age group [2]. In India, it is estimated that at around 3 cases per 1000

live births; however, being a developing country, the actual number would be much higher than the probable number. The increased survival rate of very preterm babies has resulted in an increase in the prevalence of CP. Intrauterine infection, teratogenic exposure, placental insufficiency, multiple gestation, and maternal illness like mental retardation, seizures, or hyperthyroidism are some of the perinatal risk factors for CP [3]. Parents who are given a CP diagnosis in doubt. Anxiety is piercing with the tough and persistent struggle to improve the health and development of the child, and typically leads to feelings of powerlessness and helplessness that can in turn intensify feelings of parental incapacity. Parents who had children with CP were reported by Brehaut et al. to have more physical symptoms, emotional and cognitive issues, and high and chronic stress over a long time compared to parents of normal children [4]. According to the World Health Organization (WHO, 2012), quality of life (QOL) is "an individual's perception of their position in life in relation to their goals, expectations, standards, and concerns as well as in the context of the culture and value system in which they live". Parents of CP children are commonly faced with a range of financial, social, physical, and emotional challenges. Due to their continuous support with their children's day to day activities, they are typically physically fatigued [5]. The initial stressful event in carers is diagnosis confirmation, followed subsequently by coping with the caregiving task, treatment cost, and deconstruction of the self-social life. Management of CP is performed by the multidisciplinary team with participation of the parents, particularly mothers are very important. Normally, providing such care would be detrimental to the patient's body as well as the psychological well-being of the mother and the parents and an effect on the earning, functioning, and sibling adjustment of the family. In the last 20 years, a number of researches have confirmed that mothers of children with CP are more overloaded with caregiving compared to mothers of children with no developmental disability and the general population [6,7]. Amongst the most important determinants of successful rehabilitation of the CP child are caregiver's quality of life. Therefore, the first step towards the development of treatments to aid the adaption of the family to enhance the rehabilitation process of CP children to identify the determinants that place CP children's mothers in a defined population at risk for poor quality of life. So, this study aims to assess the quality of life in mothers of study subject attending a tertiary hospital.

MATERIALS & METHODS

Study Area: The present study was conducted at Pediatrics Neurology unit of the Department of Pediatrics, Sir Sunderlal Hospital, Institute of Medical Sciences, Banaras Hindu University, Varanasi, Uttar Pradesh.

Study Design and Period of data collection: The present study was a hospital-based case control study, conducted during January 2024 to November 2024.

Study Subjects: The study subjects were categorized into two groups, cases (CP children and their mothers) and controls (Normal children and their mothers).

Definition of Cases: Clinically diagnosed children of CP and their mothers attending the OPD of the Department of Pediatrics, IMS, BHU, Varanasi.

Inclusion Criteria:

1. Age group 2-18 years irrespective of genders.
2. The CP children whose mother are alive and available to provide the data.
3. Written consent was taken from legal mother of each CP children.

Exclusion Criteria:

1. CP children with other chronic comorbidities/illness [e.g. Sequelae of inflammatory brain disorders, Chronic

renal disease, Chronic liver and lung disease, inborn errors of metabolism].
2. CP children; whose mother is suffering with chronic diseases.

Definition of Controls: Non-CP and apparently healthy children & their mothers coming to the hospital.

Inclusion Criteria:
1. Age group 2-18 years matched with cases in the intervals of 2 years and Gender is matched in 1:1 ratio
2. Written consent was taken from legal guardian of each apparently children.

The questionnaire was divided into the main following sections:
1) General demographic characteristics
2) Quality of Life of Mothers was measured by WHO Quality of Life-BREF Scale 26 items.

Sample Size Calculation: The minimum sample size was determined using the formula for two independent proportion:

$$n = \frac{[\, Z_{1-\alpha/2}\sqrt{2PQ} + Z_{1-\beta}\sqrt{(p_1q_1+p_2q_2)}]^2}{[\, p_1-p_2]^2}$$

Where,
$P=(p_1+p_2)/2$ and $Q=1-P$, $q_{1=1-}\, p_1$, $q_2=1-p_2$
p_1= Proportion in group 1
p_2= Proportion in group 2
α=Level of significance
1-β=power of study

- In this study, case and control is one to one ratio we take 5% level of significance at 2 tailed test and 90% power of study. Thus $Z_{(1-\alpha/2)} = 1.96$ and $Z_{(1-\beta)} = 1.28$
- p_1= proportion of sleep disorder in CP children=45%
- p_2= proportion of sleep disorder in non-CP children=25%
- (A Singh et.al 2022)
- Using the above formula, sample size was calculated to be 118 in each group.
- Adding the non-response rate of 5%, the required sample size was 125 in each group and total sample size for this study is 250.

Data Analysis: Data were entered and analyzed using SPSS software version 28.0. Descriptive statistics findings were expressed as range, mean, SD; Chi-square and student's t-tests were used to test statistical significance at $p<=0.05$ significance level.

RESULT

125 mothers of children with CP cases and another 125 mothers with normal children were taken as control using selection criteria. WHOQOL-BREF Questionnaire was used to collect the information. Mean age of cases with SD was 28.59± 4.47 years, range 20-45 years; and that of control was 31.07±4.65 years, range; 23-43 years. 69.6% cases and 43.2% controls were rural,30.4% cases and 56.8% controls were urban. 87.2% cases and 82.4% controls were Hindu,12.8% cases and 17.6% controls were Muslim. 51.2% of the cases lived in joint family and 48.2% lived in nuclear families; while 53.6% of controls lived in joint family and 46.4% lived in nuclear families. 49.6% of cases and 54.4% of control mothers had two children. Occupation-wise, 92% and 84.8% mothers among cases and control were home maker. Educational status of the cases ranges from illiterate (1.6%) to post-graduation degree (4.8%) while that in controls ranges from illiterate (5.6%) to post-graduation degree (11.2%). Regarding the Socio-Economic status 83.2% cases belonged to the socio-economic class III and IV and 51.2% control group belonged to the class II. No significant difference ($p>0.05$) according to religion, types of family, number of children in family and occupation were found, whereas difference were significant ($p\leq0.05$) in age, residence, educational status and socio-economic status among case and control group. (Table 1)

Mothers of both the groups were assessed for physical, psychological, social and environmental domain and the mean domain scores of the groups were compared using t-test. The difference was found significant

($p \leq 0.05$) in all domains, which implies that quality of life of mothers of children with CP were lower than that of mothers of normal children. (Table 2)

Difference in QOL score among mothers of study groups were examined in relation to family type, religion and residence. The difference in QOL among the mothers of study groups were found significant ($p \leq 0.05$) in all domains for the both families expect for the social domain in nuclear family. ($p > 0.05$). (Table 3)

The difference in QOL among mothers of study groups of different religion was found significant ($p \leq 0.05$) in all domains expects in social domain for Hindu religion and physical domain for Muslim religions. (Table 4)

The difference in QOL among mothers of study groups were found significant ($p \leq 0.05$) in all domains for both residences expect for the social domain in rural residence. (Table 5)

Table 1: Socio-demographic characteristics of study groups (n=250)

Socio-demographic characteristics of mothers	**Cases (n=125) Number (%)**	**Controls (n=125) Number (%)**	**X^2, p value**
Age (in years)			
≤25	42 (33.9)	15 (12.4)	X^2 = 22.10, p=0.000
26 – 30	47 (37.9)	48 (39.7)	
31 – 35	30 (24.2)	39 (32.2)	
≥ 36	5 (4.0)	19 (15.7)	
Mean± SD	28.59±4.47	31.07±4.65	
Residence			X^2 =17.71, p=0.000
Rural	87(69.6)	54(43.2)	
Urban	38(30.4)	71(56.8)	
Religion			
Hindu	109 (87.2)	103(82.4)	X^2 =1.11, p=0.291
Muslim	16 (12.8)	22 (17.6)	
Type of family			
Joint	64(51.2)	67(53.6)	X^2 =0.144, p= 0.704
Nuclear	61(48.8)	58(46.4)	
Mother's total no of children alive			
One	19(15.2)	19(15.2)	X^2 =4.98, p=0.289
Two	62(49.6)	68(54.4)	
Three	32(25.6)	33(26.4)	
Four or more	12(9.6)	5(4.0)	
Mother's Education			
Illiterate	2(1.6)	7(5.6)	X^2 =15.92, p=0.007
Primary	20(16.0)	21(16.8)	
High School	29(23.2)	33(26.4)	
Higher Secondary	24(19.2)	30(24.0)	
Graduation	44(35.2)	20(16.0)	
Post Graduation	6(4.8)	14(11.2)	
Occupation			
Home maker	115(92.0)	106(84.8)	X^2 =4.94, p=0.084
Others	9(7.2)	19(15.2)	
Skilled worker (handicraft/tailoring)	1(0.8)	0(0.0)	
Socio-economic status			
Class-II (Rs. 5175-10347)	21(16.8)	64(51.2)	X^2=78.06, p=0.000
Class-III (Rs. 3105-5174)	49(39.2)	61(48.8)	
Class-IV (Rs.1555-3104)	55(44.0)	0(0.0)	

Table 2: 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	
Physical	62.45	10.24	71.99	11.54	t=6.90, p=0.000
Psychological	54.63	9.17	69.80	5.91	t=15.54, p=0.000
Social	71.06	7.41	72.73	4.90	t=2.10, p=0.036
Environmental	62.82	8.15	71.28	5.69	t=9.51, p=0.000

Table 3: Comparison the QOL and Mean Domain score among the different Types of families among the cases and controls.

Type of family	Domain	Cases (Joint=64, Nuclear=61)		Controls (Joint=67, Nuclear=58)		t, p-value
		Mean Score	SD	Mean Score	SD	
Joint	Physical	61.53	8.52	71.71	12.37	t=5.46, p=0.000
	Psychological	53.79	7.73	69.20	5.41	t=13.26, p=0.000
	Social	71.43	6.38	73.11	4.45	t=2.41, p=0.016
	Environmental	62.29	8.00	71.40	5.57	t=7.58, p=0.000
Nuclear	Physical	63.42	11.77	72.31	10.59	t=4.31, p=0.000
	Psychological	55.50	10.46	70.50	6.42	t=9.35, p=0.000
	Social	70.67	8.39	72.29	5.38	t=1.24, p=0.215
	Environmental	63.37	8.35	71.15	5.86	t=5.80, p=0.000

Table 4: Comparison of the Mean Domain score of case and control among different Religion.

Religion	Domain	Cases (Hindu=109, Muslim=16)		Controls (Hindu=103, Muslim=22)		t, p-value
		Mean Score	SD	Mean Score	SD	
Hindu	Physical	63.00	9.88	72.68	10.36	t=6.96, p=0.000
	Psychological	55.09	8.94	69.63	6.10	t=13.74, p=0.000
	Social	71.62	6.97	72.77	5.16	t=1.36, p=0.175
	Environmental	63.36	8.16	71.01	5.79	t=7.83, p=0.000
Muslim	Physical	58.75	12.12	68.72	15.83	t=2.10, p=0.042
	Psychological	51.50	10.36	70.63	4.96	t=7.57, p=0.000
	Social	67.25	9.30	72.54	3.54	t=2.44, p=0.019
	Environmental	59.12	7.35	72.54	5.12	t=6.63, p=0.000

Table 5: Comparison of the Mean Domain score of case and control among different Residence

Residence	Domain	Cases (Rural=87, Urban=38)		Controls (Rural=54, Urban=71)		t, p-value
		Mean Score	SD	Mean Score	SD	
Rural	Physical	63.36	9.94	72.22	10.83	t=4.96, p=0.000
	Psychological	55.10	9.06	70.07	5.56	t=10.91, p=0.000
	Social	71.33	7.85	72.53	5.86	t=0.97, p=0.334
	Environmental	63.31	8.34	71.53	5.49	t=6.42, p=0.000
Urban	Physical	60.36	10.74	71.81	12.12	t=4.88, p=0.000
	Psychological	53.55	9.44	69.60	6.20	t=10.67, p=0.000
	Social	70.44	6.33	72.88	4.06	t=2.44, p=0.016
	Environmental	61.71	7.70	71.09	5.87	t=7.11, p=0.000

DISCUSSION

In the present study, total 125 cases and 125 controls were selected consecutively from the Department of Pediatrics, Institute of Medical Sciences, BHU Varanasi. Mean age of the case group was 28.59± 4.47 years and that of control was 31.07± 4.65 years. The mean Quality of life of cases in all domains were found significantly lower than control mothers expect for social domain. The difference in QOL among the control and case is found significant in all domains expects for the social domain for both families. Numerous studies were discovered to evaluate the quality of life of caregivers for children with cerebral palsy. The results showed that the four WHOQOL-BREF domains -physical, psychological, social interactions, and environmental – had all significantly poorer QOL scores for

caregivers of developmental delay children. The majority of carers were mothers and homemakers who had very little money and support [8]. The researcher evaluated the quality of life (QOL) of 126 family members caring for children with CP in Central India. More than half of the caregivers had low QoL in physical, social, and environmental dimensions of which the most impacted was the social QoL [9]. These findings are pertinent for several reasons. Mothers without social support, for instance, would find it difficult to find the time to engage in activities that promote health, as a result. Additionally, the QOL of caregivers is adversely affected when children in disadvantaged households with little resources experience an acute illness or chronic aliment [10]. Some studies have also found to determine if caring for the CP child also affected the physical or general health of the caregivers. A study showed that parents of children with CP had lower scores in the physical health and psychological domains compared with the control groups [11]. A study also reported that a significant worsened QOL among mothers of CP children with CP compared to the mothers of normal children [12]. Another research study indicates that rehabilitation has no appreciable effect on carer's psychological health. This study found that most carers in the non-rehabilitation group have a very poor quality of life as a result of their child's worsening health. Children's impairment levels have been connected to parental stress, which directly lowers the quality of life for carers [13,14]. In another study it was also reported that all the variables measured (ZBI, CFQ, GMFCS, and PedsQL) indicated significant differences among the different spastic groups (unilateral and bilateral CP) with p-values <0.001. However, the results indicated that mother's CB, child's GMFCS, and weariness level had a positive influence on the quality of life in the child, with the influence being more pronounced in the case of quadriplegic type children [15]. In a study the physical area ($r = -0.498$, $p < 0.0001$), psychological areas ($r = -0.486$, $p < 0.0001$), social relationships ($r = -0.165$, $p = 0.019$), and environmental areas ($r = -0.195$, $p = 0.005$) were all found to have statistically significant negative correlations with the degree of depression. For physical ($r = -0.327$, $p < 0.0001$) and psychological ($r = -0.440$, $p < 0.0001$) domains, there was a significant statistical relationship between the child's growing motor dysfunction and the mean QoL domain scores. The kid's age was the strongest risk factor that was affecting the mother's quality of life (QoL) among all the baseline demographic variables ($p = 0.041$) [16]. In another study the mean CSI score was 4.5 (SD = 3.0) in mothers of children and adolescents with GMFCS levels I and II, and 12.0 (SD = 1.3) in mothers of children and youths with GMFCS levels IV-V. The expected difference in the mean was statistically significant at 7.5 (95% CI 6.4-8.6; $p < 0.01$). Parents of young children and adolescents who require adult support for mobility (GMFCS levels IV and V) also reported more caregiver strain compared to parents of children and young adults who walk (GMFCS levels I and II) [17]. Comparing GMFCS scores of children with CP to mothers' NHP, DASH-T, RMDQ, NDI, and BAE values in an inter-group were not found to be statistically significant ($p > 0.05$). A statistically significant correlation ($p<0.05$) was found between NHP measures and mothers' lower and arm pains, and their BAI, NDI, RMDQ, and DASH-T [18]. Caregivers produced the lowest mean quality of life in the social domain (9.33±1.49 SD), followed by the psychological (18.23±1.50 SD). 70% of the parents assessed their general quality of life as neither good nor bad, and 66.67% of them were satisfied with their personal health [19]. The mean age of the 117 children was 7.62 (4.08), and 52.5% were male (n=114) and 47.5% were female (n=103). 89.3% were spastic (n=191) (78.1% bilateral, 21.9% unilateral), 5.6% ataxic (n=12), and 5.1% dyskinetic (n=11) based on the CP categories. The median SF-

12 PCS and MCS were 51.69 (25.76-62.92) and 55.36 (26.64-60.69), respectively. When SF-12 scores were compared based on the functional levels of the children, SF-12 PCS and SF-12 MCS scores varied significantly by GMFCS, MACS, CFCS, and EDACS level ($p<0.01$) [20].

CONCLUSION

The present study showed significant difference in the in all domains. The mothers having CP children scored significantly less compared to their age controls except in the social relationship domains for both families and in all domains expects in social domain for Hindu religion and physical domain for Muslim religions and in residences all domains for both residences expect for the social domain in rural residence. According to the study caregiver interventions are necessary since they may indirectly affect children with cerebral palsy. The future function of rehabilitation personnel should be investigated in study, and QOL institutions can provide more precise and in-depth data that can help with intervention planning.

Declaration by Authors

Ethical Approval: Approved
Acknowledgement: None
Source of Funding: None
Conflict of Interest: The authors declare no conflict of interest.

REFERENCES

1. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007 Feb 1;109(suppl 109):8-14.
2. World Health Organization. The World Health Organization Quality of Life assessment (WHO/QOL): position paper from the World Health Organization. Soc sci med. 1995; 41:1403-9.
3. Wu YW, Escobar GJ, Grether JK, Croen LA, Greene JD, Newman TB. Chorioamnionitis and cerebral palsy in term and near-term infants. Jama. 2003 Nov 26;290(20):2677-84.
4. Brehaut JC, Kohen DE, Raina P, Walter SD, Russell DJ, Swinton M, O'Donnell M, Rosenbaum P. The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers? Pediatrics. 2004 Aug 1;114(2): e182-91.
5. Farajzadeh A, Maroufizadeh S, Amini M. Factors associated with quality of life among mothers of children with cerebral palsy. International journal of nursing practice. 2020 Jun;26(3): e12811.
6. Barlow JH, Cullen-Powell LA, Cheshire A. Psychological well-being among mothers of children with cerebral palsy. Early Child Development and Care. 2006 May 1;176(3-4):421-8.
7. Zanon MA, Batista NA. Quality of life and level of anxiety and depression in caregivers of children with cerebral palsy. Revista Paulista de Pediatria. 2012;30 :392-6.
8. Rao A, Ramamurthy D, Kumar U. Quality of life in caregivers of children with developmental delay–A case–control study. International Journal of Health & Allied Sciences. 2021 Jan 1;10(1):48.
9. Hegde V, Jain R, Bappal A, Shambu R, Kotian H. Female care givers of children with cerebral palsy: Quality of life, knowledge and practice regarding ophthalmic evaluation–A study from coastal town of Southern India. J Clin Diagn Res. 2018 Aug 1;12.
10. Christian BJ. Translational Research-The Intersection Between Sociocultural and Environmental Factors and the Health of Children and Families. Journal of Pediatric Nursing. 2017 Oct 5;37: 127-31.
11. Romeo DM, Cioni M et al. Quality of life in parents of children with cerebral palsy: is it influenced by the child's behaviour? Neuropediatrics. 2010 Jun; 41(3):121-6.
12. Ones K, Yilmaz E, Cetinkaya B, Caglar N. Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). Neurorehabilitation and neural repair. 2005 Sep;19(3):232-7.
13. Al-Mutayliq A, Yeowell G, Fatoye F. The impact of rehabilitation on parents and caregivers of children with cerebral palsy: a systematic review. 2016 Nov 12.
14. Shirmard MH, Seyyedi M, Toopchizadeh V, Ghojazadeh M. Low Quality of Life and its Associated Risk Factors in Parents of Children with Cerebral Palsy in the

Northwest of Iran; A Case Control Study. J Clin Anal Med. 2017;8(5):431-5.
15. Mohammed SS, Abdelwahab MS, Zaky NA, Abdelazeim FH. Impact of mother's care burden, fatigue and Child's functional level on quality of life in spastic cerebral palsy. Physiotherapy Research International. 2024 Jan;29(1):e2067.
16. Sonune SP, Gaur AK, Shenoy A. Prevalence of depression and quality of life in primary caregiver of children with cerebral palsy. Journal of family medicine and primary care. 2021 Nov 1;10(11):4205-11.
17. Prakash V, Patel AM, Hariohm K, Palisano RJ. Higher levels of caregiver strain perceived by Indian mothers of children and young adults with cerebral palsy who have limited self-mobility. Physical & occupational therapy in pediatrics. 2017 Jan 1;37(1):64-73.
18. Kavlak E, Altuğ F, Büker N, Şenol H. Musculoskeletal system problems and quality of life of mothers of children with cerebral palsy with different levels of disability. Journal of back and musculoskeletal rehabilitation. 2015 Nov;28(4):803-10.
19. Chalipat S, Malwade SD, Karambelkar GR, Agarkhedkar SR, Kannan VT. Assessment of quality of life of parents of children with cerebral palsy. Journal of Evidence based Medicine and Healthcare. 2016;3(85):4673-7.
20. Karatekin BD, Icagasioglu A. The effects of the functional levels of children with cerebral palsy on the quality of life of caregivers. Journal of Surgery and Medicine. 2022 Feb 15;6(2):191-5.

How to cite this article: Mohd Ghalib Khan, Tej Bali Singh, Rajniti Prasad. Quality of life of mothers of children with cerebral palsy attending in a Tertiary Care Hospital in Eastern UP. *Int J Health Sci Res.* 2025; 15(8):1-13. DOI: *https://doi.org/10.52403/ijhsr.20250801*

******