

Original Article

Quality of life of caregivers of children with cerebral palsy in Assam, India

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ABSTRACT

Background: Cerebral palsy (CP) is a common childhood disability worldwide that places significant demands on caregivers. Empirical evidence on caregiver strain is scarce in India. This cross-sectional study assessed the quality of life (QOL) of 140 purposively chosen caregivers of children aged 4-12 with CP in Assam, India, using the WHOQOL-BREF questionnaire. **Methods:** Subscale scores were computed with reliability confirmed using Cronbach's α . Spearman's rank correlation and chi-square tests were performed to investigate the associations of caregiver and child characteristics with the QOL of caregivers. **Results:** The overall QOL score was 48.46 ± 11.49 , with 82% of caregivers reporting poor QOL. Significant variations in QOL were associated with parental education, father's occupation, perceived parental physical and mental health, social isolation, awareness of social services, child's GMFCS levels, special school enrolment, associated conditions, and social support. Spearman's rank correlation revealed that the father's age, mother's years of schooling, GMFCS levels, and associated conditions of the child were correlated with the QOL of caregivers. **Conclusions:** Community-level awareness generation programs, establishment of an affordable special school, and increased enrolment, along with a disability-friendly health system, will enhance the QOL of the caregivers.

Key words: Quality of life, Cerebral Palsy, Caregivers, Assam, India

Cerebral palsy (CP) is a non-progressive neurodevelopmental disorder affecting movement, muscle tone, and motor skills due to injury to brain development (1) and can lead to abnormalities in intellectual abilities, vision, and speech (2). CP is the most prevalent physical disability in children, affecting 2.1 per 1000 live births (3), with developed countries having lower CP rates than developing countries (4). The impairments associated with CP significantly impact on quality of life (QOL), limiting participation in age-appropriate activities and normal growth and development (5). CP has no cure, although its effects can be lessened with physiotherapy, medical treatments, and therapies (6). Thus, children with CP rely on caregivers for basic requirements, causing considerable emotional, physical, and financial burden (7-9). However, caregiving for children with CP is often neglected (10). While providing care for a young child is a normal parental role, when a child has functional limits and long-term dependence, it assumes greater importance (11).

The World Health Organisation (WHO) defines QOL as an individual's view of their position within the cultural framework and value systems in which they live, along with

goals, expectations, standards, and concerns (12). Caring for a child involves psychosocial challenges, including inadequate facilities, unsupportive interactions, social limitations, seclusion, intrapersonal conflict, and loneliness (13-15). Assam, in northeast India, has poor maternal and child health indicators and an inadequate healthcare infrastructure (16-18) increases the vulnerability of children being born with CP and the demand for caregivers. However, limited research exists on the caregivers' QOL in this region (19). Thus, this study assesses the QOL of caregivers of children with CP in Assam and the factors influencing it.

MATERIAL AND METHODS

2.1 Design and data

This cross-sectional study was conducted in 2023 among caregivers of children with CP in Assam, India. Since CP has a low prevalence rate, a purposive sampling design was used. Three special schools and one rehabilitation center consented to participate. All caregivers of children aged 4-12 years with a clinical diagnosis of CP and at least six months of caregiving were invited, and 140 consented and were

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interviewed. Ethical permission was obtained from the Students' Research Ethics Committee (SREC) of the author's university. Interviews were conducted in Assamese, using a bilingual format with English as the second language.

2.2 Outcome variable

The outcome variable was the QOL of caregivers, categorized into 'poor' and 'good.' It was measured using the WHO Quality of Life-BREF (WHOQOL-BREF) Questionnaire, consisting of 26 questions in four domains: physical health, psychological, social relationships, and environment. All items were initially rated on a 1–5-point scale and transformed to a 0–100 scale, with higher scores indicating better QOL per the manual (12). Then, the algebraic mean of item values was calculated for each domain, and the overall QOL score was derived from the average of domain scores. Cronbach's alpha (>0.7) confirmed the reliability of the questionnaire.

2.3 Predictor variables

Predictor variables included caregiver characteristics (age, education, occupation, perceived health, religion, caste, family structure, social isolation/discrimination, awareness of social support and government schemes) and child characteristics (age, gender, siblings, type of CP, GMFCS level, associated conditions, other health problems, and school enrolment). GMFCS Group 1 (levels I-II) included movements without support, and Group 2 (levels III-V) included movements with support. Information was provided by the primary caregiver, usually the mother, who also reported on the father's details.

2.4 Statistical analysis

Stata/SE (v16.0) was used to analyse the data with a 5% significance level. Each subscale score was computed to

determine the overall QOL score. The Kruskal-Wallis test determined statistical differences in QOL based on various characteristics, and Dunn's test performed pairwise comparisons. Spearman's rank correlation (ρ) (20) investigated relationships between ordinal characteristics and QOL scores, and chi-square analysis assessed associations between categorical variables.

RESULTS

3.1 Consistency and reliability of the WHOQOL-BREF questionnaire

Cronbach's alpha was >0.7 for all four domains—physical, psychological, social, and environmental, establishing validity. Thus, the overall QOL score was calculated using all domains of the WHOQOL-BREF questionnaire.

3.2 Effect of various characteristics of caregivers on their QOL scores

The overall QOL score was 48.46 ± 11.49 (Table 1). QOL varied significantly with years of schooling of father and mother, father's occupation, and perceived physical and mental health of father and mother. However, when mean QOL scores were compared, fathers with >10 years of schooling and mothers with ≥ 9 had higher QOL scores than less educated groups. Similarly, fathers in secondary and tertiary sectors had higher scores than those in the primary sector. Caregivers reporting father's or mother's perceived physical and mental health as normal or good had significantly higher QOL than those reporting poor health. Caregivers without social isolation/discrimination, and those aware of social support and information groups, also had higher QOL.

Table 1: Effect of individual, household, and community-level characteristics of caregivers on their QOL scores

Characteristics	QOL scores		Kruskal-Wallis's test (p)	Dunn's test (p)	n
	Mean	SD			
Overall	48.46	11.49			
Relationship to the child with CP			0.299		
Mother	47.92	11.61			109
Father	50.36	11.02			31
Current age of father[^]			0.156		
≤34 years	46.61	10.19			51
35-44 years	49.01	12.69			65
>44 years	52.11	9.28			22
Current age of mother			0.080		
≤24 years	43.38	14.04			16
25-34 years	48.44	11.14			97
>34 years	51.52	10.38			27
Years of schooling of father			0.033 ^a		
≤8	47.81	10.42		≤8 vs 9-10, p= 0.555	43
9-10	45.26	13.24		≤8 vs >10, p=0.282	41
>10	51.30	10.34		9-10 vs >10, p=0.027 ^a	56
Years of schooling of mother			0.002 ^a		

≤8	43.68	12.74		≤8 vs 9-10, p= 0.008 ^a	46
9-10	50.62	9.78		≤8 vs >10, p=0.005 ^a	47
>10	50.97	10.50		9-10 vs >10, p=0.987	47
Occupation of father[^]			0.000 ^a		
Primary sector	44.35	11.58		Primary vs Secondary, p=0.005 ^a	68
Secondary sector	51.76	9.23		Primary vs Tertiary, p=0.000 ^a	31
Tertiary sector	53.55	9.95		Secondary vs Tertiary, p=0.763	39
Occupation of mother			0.292		
Homemaker	48.02	11.54			118
Primary sector	50.83	11.16			22
Suffering from any health issue			0.363		
No	49.63	11.16			51
Yes	47.79	11.68			89
Perceived physical health of father[^]			0.000 ^a		
Poor	38.24	8.60		Poor vs Normal, p=0.000 ^a	32
Normal	48.90	9.54		Poor vs Good, p= 0.000 ^a	74
Good	58.33	8.77		Normal vs Good, p=0.000 ^a	32
Perceived physical health of mother			0.000 ^a		
Poor	39.08	9.84		Poor vs Normal, p=0.000 ^a	52
Normal	51.97	8.26		Poor vs Good, p= 0.000 ^a	60
Good	58.36	7.00		Normal vs Good, p=0.004 ^a	28
Perceived mental health of father[^]			0.000 ^a		
Poor	42.76	10.04		Poor vs Normal, p=0.000 ^a	74
Normal	54.74	8.24		Poor vs Good, p= 0.000 ^a	49
Good	57.49	10.76		Normal vs Good, p=0.591	15
Perceived mental health of mother			0.000 ^a		
Poor	43.40	10.43		Poor vs Normal, p=0.000 ^a	80
Normal	54.57	8.76		Poor vs Good, p= 0.000 ^a	43
Good	56.80	10.27		Normal vs Good, p=0.715	17
Religion			0.193		
Hindu	49.60	11.82			77
Non-Hindu	47.06	11.02			63
Caste			0.624		
ST/SC/OBC	47.82	11.84			50
Non-ST/SC/OBC	48.82	11.34			90
Family structure			0.226		
Nuclear	49.88	13.17			57
Joint/Extended	47.48	10.14			83
Experienced social isolation/discrimination			0.000 ^a		
No	56.06	7.48			53
Yes	43.83	11.06			87
Feel comfortable traveling in public transport with the child			0.075		
No	46.78	11.46			72
Yes	50.24	11.33			68
Aware of social support & information groups			0.006 ^a		
No	47.06	11.65			110
Yes	53.58	9.38			30
Aware of the government disability pension scheme			0.687		
No	49.69	8.51			13
Yes	48.33	11.77			127

Note: ^ap<0.05

[^]Current information on the two fathers is missing as they are not alive

3.3 Effect of various characteristics of children on caregivers' QOL scores

Table 2 showed that caregivers with children in GMFCS Group 1, enrolled in special schools, without other health

problems, with available inclusive spaces, and receiving pleasant behaviour from relatives and neighbours had higher QOL scores. QOL varied significantly with the number of associated conditions; caregivers of children with ≤ 1 condition had higher QOL scores than those with 2 or >2 .

Table 2: Effect of individual, household, and community level characteristics of children on QOL scores of caregivers (n=140)

Characteristics	QOL scores		Kruskal-Wallis's test (p)	Dunn's test (p)	n
	Mean	SD			
Overall	48.46	11.49			
Gender			0.364		
Male	47.76	11.60			86
Female	49.58	11.31			54
Age			0.278		
4-6 years	47.38	11.50			93
7-9 years	50.01	11.32			23
10-12 years	51.16	11.47			24
Type of CP			0.943		
Spastic	48.49	11.77			111
Non-Spastic	48.32	10.53			29
GMFCS Level			0.000 ^a		
Group 1	58.66	6.66			40
Group 2	44.38	10.43			100
Enrolled in special school			0.000 ^a		
No	45.69	11.24			96
Yes	54.49	9.66			44
Associated conditions			0.000 ^a		
≤ 1	57.94	6.40		≤ 1 vs 2, p=0.000 ^a	32
2	48.88	9.46		≤ 1 vs >2 , p=0.000 ^a	63
>2	41.12	11.88		2 vs >2 , p=0.000 ^a	45
Had other health problems			0.000 ^a		
No	51.15	10.45			91
Yes	43.46	11.75			49
Have siblings			0.178		
No	47.27	12.57			77
Yes	49.91	9.91			63
Relatives' behaviour toward child			0.000 ^a		
Unpleasant	35.48	7.68			29
Pleasant	51.85	9.79			111
Neighbours' behaviour toward child			0.000 ^a		
Unpleasant	41.56	11.21			51
Pleasant	52.41	9.68			89
Availability of inclusive spaces in the society			0.006 ^a		
No	46.07	11.58			77
Yes	51.38	10.75			63

Note: ^ap<0.05

^Current information on the two fathers is missing as they are not alive

3.4 Correlation between caregivers' QOL scores and various characteristics of the caregivers and their children

Spearman's correlation (Table 3) revealed a strong negative correlation between GMFCS levels and QOL, with associated conditions showing a moderate negative correlation. Specifically, higher scores indicated reduced caregiver QOL. Father's age and mother's years of schooling had weak positive correlations, i.e., as scores increased, caregiver QOL also increased.

Table 3: Correlation between caregivers' QOL scores and various characteristics of the caregivers and their children

Characteristics	rho value	p value
Age of the child	0.135	0.165
GMFCS level	-0.682	0.000 ^a
Associated conditions	-0.494	0.000 ^a
Current age of father [^]	0.204	0.036 ^a
Current age of the mother	0.175	0.070
Years of schooling of the father	0.138	0.155
Years of schooling of the mother	0.254	0.008 ^a

Note: ^ap<0.05

[^]Current information on the two fathers is missing as they are not alive

3.5 QOL status of caregivers by their background characteristics

Overall, 82% of the caregivers had poor QOL. Most fathers (91%) in the primary sector, 97% with perceived poor physical health, and 96% with poor mental health had poor QOL. Among mothers, 96% with poor physical health and 96% with poor mental health had poor QOL. Eighty-eight percent of caregivers in joint/extended families and 91% experiencing social isolation/discrimination had poor QOL.

3.6 QOL status of caregivers by the background characteristics of their children

Among child-related factors, 93% of caregivers of children in GMFCS group 2 and 88% of those not enrolled in special schools had poor QOL. Ninety-six percent of caregivers of children with >2 associated conditions and 94% with other health problems had poor QOL. All caregivers of children facing unpleasant behaviour from relatives (100%) and most experiencing unpleasant behaviour from neighbours (94%) reported poor QOL.

DISCUSSION

The study found that most caregivers of children with CP had low QOL. QOL varied considerably with years of schooling of father and mother, father's occupation, perceived physical and mental health of father and mother, social isolation/discrimination, availability of inclusive spaces, awareness about social support groups, GMFCS levels, enrolment in a special school, associated conditions, other health problems, and behaviour of relatives and neighbours. The child's GMFCS levels and associated conditions demonstrated a negative correlation, and the father's age and mother's years of schooling demonstrated a positive correlation with caregivers' QOL.

The QOL of caregivers varied with the father's and mother's years of schooling, similar to prior studies showing better QOL in caregivers with higher education. Higher education enables better understanding of illness, employ coping, and utilization of resources (21,22). Fathers with higher age reported better QOL, possibly due to greater emotional resilience and coping ability. Father's occupation was associated with caregivers' QOL, consistent with findings that low income from primary-sector jobs increases caregiving's financial strain and limits access to child healthcare (22), reducing caregivers' QOL. Caregivers' QOL varied with family structure; aligning with evidence that a dysfunctional family compromised caregiver health and quality of care (23). Social isolation/discrimination lowered caregivers' QOL, while strong family and community networks, common in Indian culture, enhanced coping with

caregiving stress and healthcare needs (24,25). Awareness of social support and information groups improved QOL, as peer connections and emotional sharing help caregivers cope (26). GMFCS levels were negatively associated with QOL, consistent with findings that severe disability increases caregiver's stress and physical strain (27). Enrolment in special schools improved caregivers' QOL, as these institutions share caregiving duties and train the children in daily activities and functional academics (28). Associated conditions and other health problems of CP children lowered caregivers' QOL, consistent with previous findings that multiple disabilities increase caregiver burden (29). Positive behaviour of relatives and neighbours improved caregivers' QOL, as non-supportive social environments increase caregiver stress and stigma (10,30). Caregivers reporting inclusive spaces showed better QOL, supporting evidence that non-inclusive environments restrict mobility and social participation (10).

The study has notable strengths, including population-based recruitment that enhances external validity, a narrow participant age range that improves interpretability, and the use of caregiver interviews to provide valuable insights into QOL. However, it also has limitations such as the purposive sampling approach, small sample size, and restricted age range, all of which may limit generalizability. Larger, regionally diverse studies are needed to further validate and expand these findings.

CONCLUSION

Caregivers of children with CP experience significantly lower QOL, influenced by several modifiable caregiver and child-related factors. Community-level awareness generation programs, establishment of an affordable special school, and increased enrolment, along with a disability-friendly health system, will enhance the QOL of the caregivers.

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