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Quality of Life Among Caregivers of Children with Cerebral Palsy Versus Neurotypical Children: A Cross-Sectional Analysis

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Abstract

Background: *Caring for a child with cerebral palsy (CP) imposes substantial physical, psychological, social, and environmental challenges, significantly affecting caregivers' quality of life (QoL). While caregiver burden in CP has been widely studied, few studies have compared QoL in CP caregivers versus neurotypical kids using standardized instruments.*

Objective: *To compare QoL across the four WHOQOL-BREF domains between CP caregivers and parents of neurotypical kids.*

Methods: *A cross-sectional comparative study was conducted involving 55 CP caregivers and 55 caretakers of neurotypical children. QoL was measured using WHOQOL-BREF (Physical, Psychological, Social, Environmental domains). Independent t-tests were performed for group comparisons.*

Results: *CP Caregivers reported significantly lower QoL across all domains compared to caregivers of neurotypical children ($p<0.001$). The largest disparities were observed in the psychological and environmental domains, indicating heightened emotional stress and social isolation.*

Conclusion: *CP Caregivers experience substantially poorer QoL across all dimensions. Targeted psychosocial, physical, and environmental interventions are urgently required to support this vulnerable population.*

Keywords: *Cerebral palsy, Caregivers, Quality of life, WHOQOL-BREF, Caregiver burden*

INTRODUCTION

Cerebral palsy (CP) is a collection of persistent yet non-progressive mobility and postural problems caused by disruptions in the developing brain of a fetus or child(1). It is still the most prevalent cause of physical handicap in children around the world, with an estimated rate of 2 to 3 per 1,000 live births though regional variations exist depending on healthcare access, perinatal care, and socioeconomic development (2,3). In India, prevalence rates are reported to be higher due to limited neonatal intensive care services and increased perinatal risk factors (4).

Children with CP frequently present with associated impairments beyond motor dysfunction, including cognitive deficits, epilepsy, visual and hearing impairments, speech and communication problems, and behavioral challenges (5,6). These comorbidities add to the complexity of caregiving and often extend the demands on families beyond physical assistance to include medical coordination, emotional support, and lifelong dependency (7).

Caregivers, most often mothers, play a central role in the upbringing and daily management of children with CP. However, caregiving for a child with CP differs considerably from typical parenting. It requires sustained physical effort, such as lifting, transferring, and assisting with daily activities, which often leads to musculoskeletal strain and fatigue (8,9). In addition, caregivers frequently experience emotional distress, anxiety, depression, and a sense of social isolation due to reduced participation in social and recreational activities (10–12). The financial implications are also profound, as long-term medical care, therapy, assistive devices, and reduced employment opportunities for caregivers create significant economic strain (13,14).

The combination of these problems has a direct impact on caregivers' quality of life (QoL). The World Health Organization defines Quality of Life (QoL) as "an individual's perception of their position in life within the framework of the cultural and value systems they inhabit, and in relation to their goals, expectations, standards, and concerns" (15). The WHOQOL-BREF instrument is extensively utilized to assess quality of life across four domains: physical, psychological, social, and environmental health, and has undergone validation in many populations, including caregivers of children with chronic illnesses (15,16).

A systematic review and other studies have shown that parents of children with cerebral palsy (CP) endure increased psychological discomfort, diminished life satisfaction, and poorer engagement in community activities relative to control groups (17,18). Moreover, musculoskeletal pain among caregivers is a growing concern, with evidence showing high rates of back and shoulder pain directly linked to caregiving duties (19). Psychological outcomes such as depression, anxiety, and emotional burnout are consistently reported amongst caregivers, especially among mothers, who are disproportionately affected (19,20). Caregivers also report feelings of social exclusion, marital strain, and diminished leisure opportunities, further compounding their reduced QoL (21,22). Financial stress is another problem, especially in low- and middle-income nations where families have to pay for a lot of their own medical care and rehabilitation.

Previous research demonstrates that caregivers of children with CP or intellectual disabilities have increased stress and lower QoL compared to caregivers of typically developing children (23-27) Even if there is more and more data, many studies have problems because they don't have enough participants, don't have control groups, or only look at one aspect of quality of life instead of a more comprehensive view. Moreover, recent findings emphasize the bidirectional impact of caregiving where caregiver well-being directly influences the child's rehabilitation outcomes and family functioning (28,29). More recent evidence highlights the compounded risks faced by CP caregivers, including chronic musculoskeletal disorders, elevated psychological distress, reduced social participation (30-33)

Due to these constraints, a systematic comparison of quality of life domains between parental caregivers of children with cerebral palsy and those of neurotypical children is needed. . Such evidence can inform targeted interventions aimed at supporting caregivers, improving their well-being, and ultimately enhancing child outcomes. The objective of this study was to assess and compare the quality of life across the four WHOQOL-BREF measures between caregivers of children with cerebral palsy and those of neurotypical children. We anticipated that caregivers of children with cerebral palsy would indicate a markedly reduced quality of life across all metrics in comparison to controls.

METHODOLOGY

This cross-sectional study involved 55 caregivers of children suffering from Cerebral Palsy and 55 caregivers of neurotypical children in Mumbai. Participants have been chosen from families utilizing specialist services in rehabilitation centres and educational institutions from February 2024 to January 2025. Participants were recruited via convenience sampling and subsequently evaluated based on established inclusion and exclusion criteria.

The study population consisted of informal, unpaid caregivers of all genders, aged between 20 and 50 years. Inclusion criteria consisted actively involved in providing primary care to the child with MMSE>23. Group A: Caregivers (≥18 years) of children diagnosed with CP, categorized according to Gross Motor Function Classification System (GMFCS I–V).Group B: Age- and sex-matched caregivers of neurotypical children. Caregivers with chronic medical conditions and undergoing psychiatric management or those unwilling to participate were excluded from the study. All eligible participants provided informed consent before being enrolled. Sample Size: Determined based on effect sizes from previous studies, ensuring 80% power and 5% significance.

The caregivers were informed about the study's main purpose, the importance of their contribution, the confidentiality of their responses, the estimated time required for completing the survey, and the issues addressed within the questionnaire. Following this information, caregivers voluntarily participated in the survey. Detailed interviews were conducted, using a specially designed questionnaire to gather socio-demographic characteristics of both caregivers and their children. Information collected included the child's age and gender, the caregiver's age, gender, education, annual family income, hours spent on caregiving, the number of other dependent family members, and any additional help received in caregiving. The type of CP and the child's motor function level were recorded.

Data Collection Tool:

QoL was assessed using the WHOQOL-BREF (26 items, 4 domains: Physical, Psychological, Social, Environmental). Scores were transformed to a 0–100 scale, higher values representing better QoL.

Methodology for Statistical Analysis

All the collected data was entered, cleaned and coded in Microsoft Excel 2021 (©Microsoft Inc.). Data analysis was carried out in SPSS v21 (©IBM Inc.). For quantitative variables, descriptive statistics were shown as mean ± SD, and for categorical variables, they were shown as median, interquartile range (IQR), and frequencies with percentages. The Shapiro–Wilk test was used to check for normality ($p < 0.05$ means that it wasn't normal). We used the Independent t test for parametric data, the Mann–Whitney U test for non-parametric data, and the Chi-square test for categorical variables to compare groups. A p value of less than 0.05 was deemed statistically significant.

RESULTS

This comparative study conducted on primary caregivers of 110 children yielded the following results:

A) Socio-demographic characters:

The caregivers were divided into two equal groups of 55: Group A (caregivers of children with CP) and Group B (caregivers of normal children). In Group A, most caregivers were aged 31–40 years (n = 33, 60.0%), while in Group B, the majority also belonged to the 31–40 years group (n = 29, 52.7%). The mean age of caregivers was 37.93 ± 5.02 years in Group A and 39.58 ± 4.78 years in Group B. The difference was not statistically significant (t = -1.771, df = 108, p = 0.079).

Regarding caregiver qualification, in Group A, 3.6% were illiterate, 18.2% had primary education, 29.1% completed SSC, 12.7% completed HSC, and 36.4% were graduates or above. In Group B, the respective proportions were 5.5%, 9.1%, 27.3%, 30.9%, and 27.3%. The distribution of educational levels did not differ significantly between groups ($\chi^2 = 6.780$, df = 4, p = 0.148). For occupation, 70.9% of caregivers in Group A and 76.4% in Group B were housewives, while 29.1% and 23.6%, respectively, were employed. No significant difference was observed ($\chi^2 = 0.421$, df = 1, p = 0.516).

With respect to the number of dependent family members, in Group A, 20.0% reported none, 70.9% reported one, 7.3% reported two, and 1.8% reported three. In Group B, 18.2% reported none, 76.4% reported one, and 5.5% reported two. The intergroup difference was not statistically significant ($\chi^2 = 1.302$, df = 3, p = 0.840).

The average time spent in caregiving per day was significantly higher in Group A (mean = 11.09 ± 4.95 hours, median = 12) compared to Group B (mean = 4.82 ± 2.54 hours, median = 4), and this difference was statistically significant (Mann–Whitney U test, Z = -6.090, $p < 0.001$). In terms of receiving help with caregiving, 65.5% of caregivers in Group A and 78.2% in Group B reported no help, while 34.5% and 21.8%, respectively, reported receiving assistance. The difference was not significant ($\chi^2 = 2.201$, df = 1, p = 0.138).

The caregiver's relationship with the child was predominantly maternal in both groups (81.8% in Group A and 80.0% in Group B), with fathers contributing in 18.2% and 20.0% of cases, respectively. No significant difference was observed between groups ($\chi^2 = 0.059$, df = 1, p = 0.808).

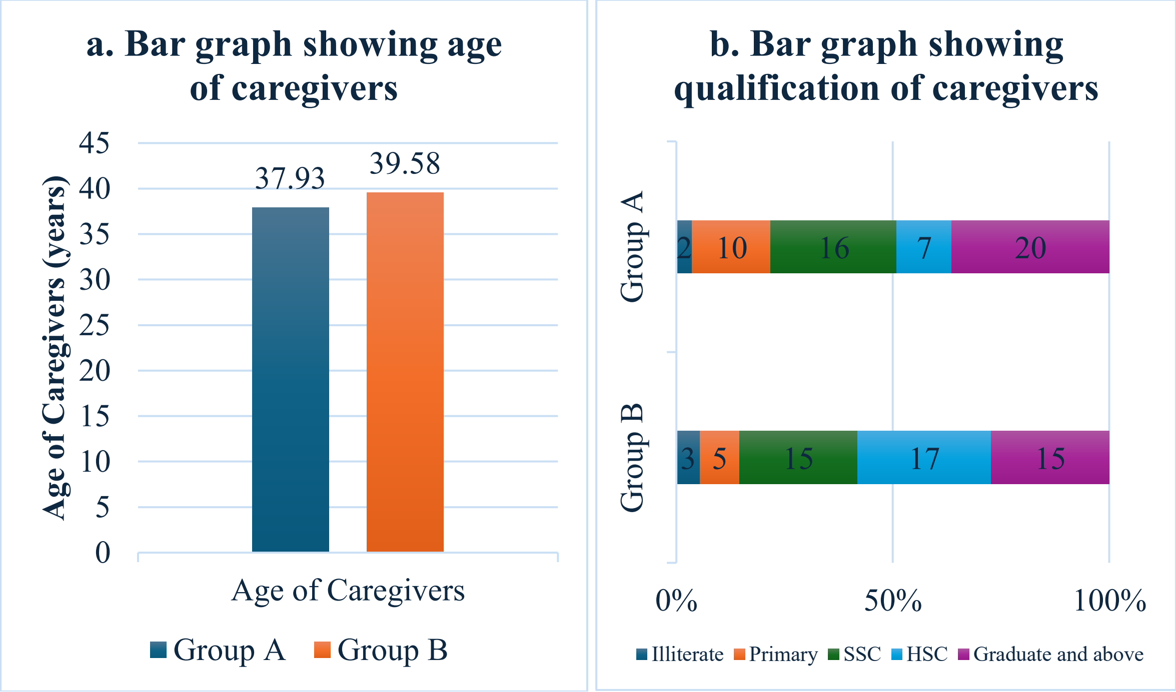
The mean age of children was 10.07 ± 3.18 years in Group A and 9.65 ± 3.30 years in Group B, with no significant intergroup difference (t = 0.676, df = 108, p = 0.500). In Group A, spastic diplegic CP was most common (n = 33, 60.0%), followed by spastic quadriplegic (n = 9, 16.4%), spastic hemiplegic (n = 8, 14.5%), and dystonic CP (n = 5, 9.1%). On the Gross Motor Function Classification System (GMFCS) scale, most children were rated level 3 (n = 19, 34.5%), followed by level 2 (n = 15, 27.3%) and level 4 (n = 13, 23.6%).

Table 1: Descriptive and Comparative Analysis of Socio-Demographic and Caregiving-Related Factors between Group A and Group B

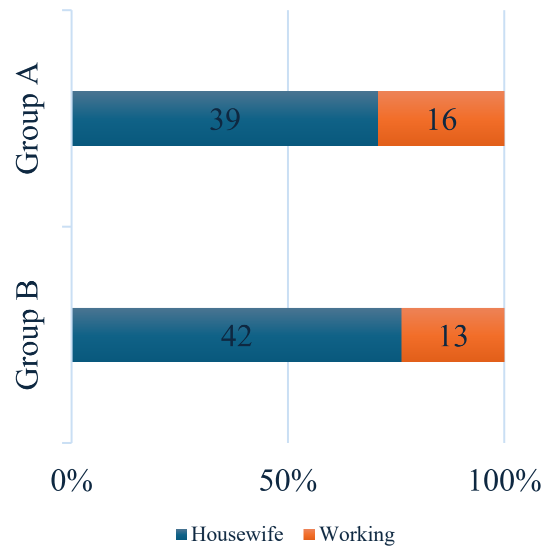
Variable		Group A (n = 55)	Group B (n = 55)	Test statistics for intergroup comparison	Significance (p value)
Age of caregiver (years)	Mean ± SD	37.93 ± 5.02	39.58 ± 4.78	Independent t Test t = -1.771, df = 108	0.079
Qualification of caregiver n (%)	Illiterate	2 (3.6%)	3 (5.5%)	Chi-Square Test $\chi^2 = 6.780$, df = 4	0.148
	Primary	10 (18.2%)	5 (9.1%)		
	SSC	16 (29.1%)	15 (27.3%)		
	HSC	7 (12.7%)	17 (30.9%)		
	Graduate and above	20 (36.4%)	15 (27.3%)		

Occupation of caregiver n (%)	Housewife	39 (70.9%)	42 (76.4%)	Chi-Square Test χ^2 = 0.421, df = 1	0.516
	Working	16 (29.1%)	13 (23.6%)		
No. of dependent family members n (%)	Zero	11 (20.0%)	10 (18.2%)	Chi-Square Test χ^2 = 1.302, df = 3	0.840*
	One	39 (70.9%)	42 (76.4%)		
	Two	4 (7.3%)	3 (5.5%)		
	Three	1 (1.8%)	0 (0.0%)		
Time spent in caregiving (hours)	Mean ± SD Median	11.09 ± 4.95; 12.00	4.82 ± 2.54; 4.00	Mann-Whitney U Test Z = -6.090	<0.001
Help in caregiving n (%)	No	36 (65.5%)	43 (78.2%)	Chi-Square Test χ^2 = 2.201, df = 1	0.138
	Yes	19 (34.5%)	12 (21.8%)		
Relation with child n (%)	Father	10 (18.2%)	11 (20.0%)	Chi-Square Test χ^2 = 0.059, df = 1	0.808
	Mother	45 (81.8%)	44 (80.0%)		
Age of child (years)	Mean ± SD	10.07 ± 3.18	9.65 ± 3.30	Independent t Test t = 0.676, df = 108	0.500

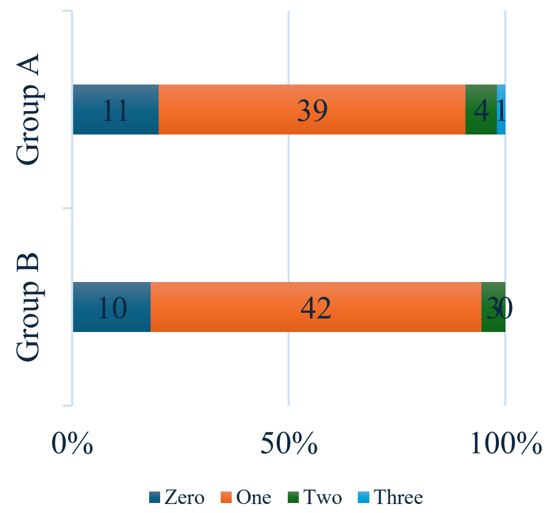
Figure 1: Bar Graphs Showing Socio-Demographic and Caregiving-Related Factors



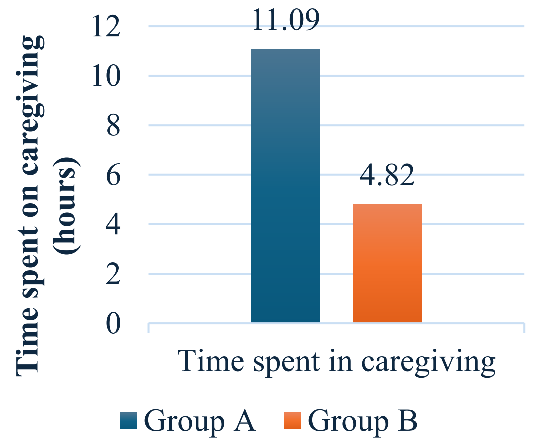
c. Bar graph showing occupation of caregivers



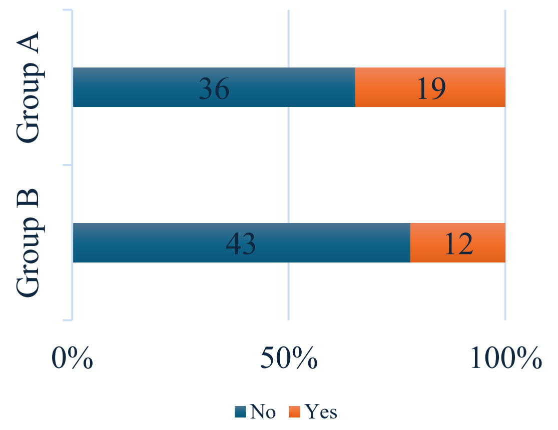
d. Bar graph showing number of dependent family members



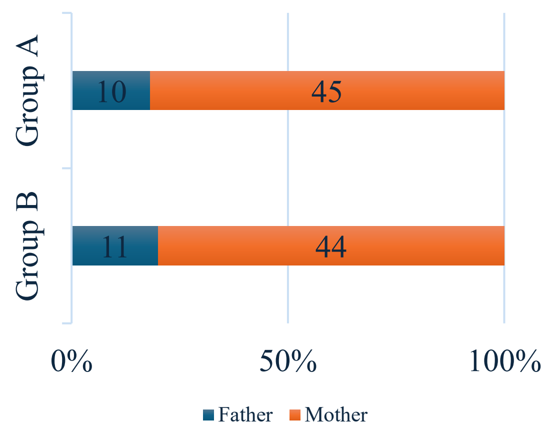
e. Bar graph showing time spent on caregiving



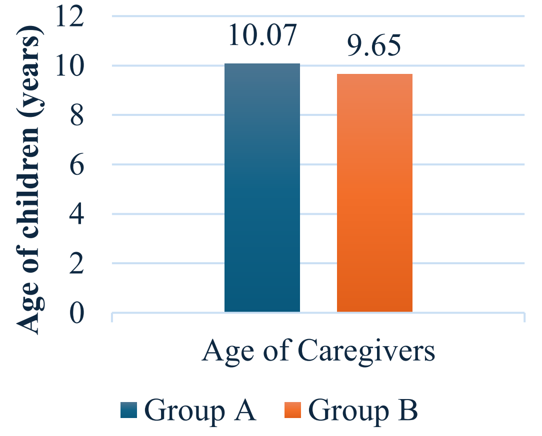
f. Bar graph showing help in caregiving



g. Bar graph showing relation to child



h. Bar graph showing age of children



B) QOL in parents of children with cerebral palsy using WHO BREF Scale

Among parents of children with cerebral palsy (Group A), the mean scores were 34.27 ± 14.46 for physical health, 34.78 ± 16.78 for psychological health, 25.13 ± 17.19 for social relations, and 34.51 ± 10.93 for environment; all domains showed non-normal distribution ($p < 0.05$). In contrast, among parents of normal children (Group B), the mean scores were 53.75 ± 12.64 for physical health, 54.60 ± 15.38 for psychological health, 50.71 ± 10.14 for social relations, and 54.25 ± 9.22 for environment, with all domains also showing non-normal distribution ($p < 0.05$) (Tables 2-3).

Table 2: Descriptive Analysis of QOL in Parents of Children with Cerebral Palsy Using WHO BREF Scale (Group A; N = 55)

QOL by WHO BREF Scale (domain scores)	Mean ± SD	Median (IQR)	Shapiro Wilk Test (p value)	Normality Distribution
Physical health	34.27 ± 14.46	31.00 (19.00, 50.00)	<0.001	Non-normal
Psychological health	34.78 ± 16.78	31.00 (25.00, 56.00)	0.001	Non-normal
Social relation	25.13 ± 17.19	25.00 (6.00, 38.00)	<0.001	Non-normal
Environment	34.51 ± 10.93	31.00 (31.00, 44.00)	0.004	Non-normal

Table 3: Descriptive analysis of QOL in parents of normal children using WHO BREF Scale (Group B; n = 55)

QOL by WHO BREF Scale (domain scores)	Mean ± SD	Median (IQR)	Shapiro Wilk Test (p value)	Normality Distribution
Physical health	53.75 ± 12.64	50.00 (44.00, 63.00)	0.002	Non-normal
Psychological health	54.60 ± 15.38	50.00 (44.00, 75.00)	<0.001	Non-normal
Social relation	50.71 ± 10.14	50.00 (44.00, 63.00)	<0.001	Non-normal
Environment	54.25 ± 9.22	50.00 (50.00, 63.00)	0.001	Non-normal

Table 3: Intergroup Comparison of QOL in Parents of Children with Cerebral Palsy And Parents Of Normal Children Using WHO BREF Scale

QOL by WHO BREF Scale (domain scores)	Group A (Mean ± SD)	Group B (Mean ± SD)	Test statistics by Mann-Whitney U Test	Significance (p value)
Physical health	34.27 ± 14.46	53.75 ± 12.64	Z = -6.030	<0.001
Psychological health	34.78 ± 16.78	54.60 ± 15.38	Z = -5.359	<0.001
Social relation	25.13 ± 17.19	50.71 ± 10.14	Z = -6.590	<0.001
Environment	34.51 ± 10.93	54.25 ± 9.22	Z = -7.725	<0.001

Intergroup comparison of quality of life (QOL) scores between parents of children with cerebral palsy (Group A) and parents of normal children (Group B) showed statistically significant differences across all domains of the WHO-BREF scale.

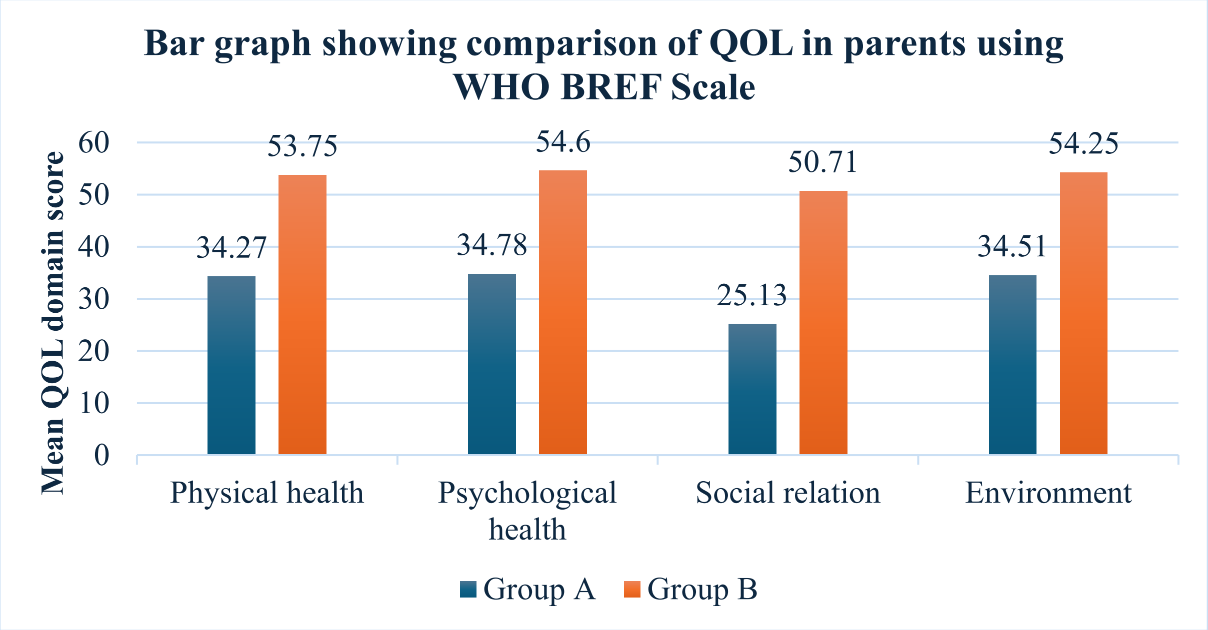
The mean physical health score was 34.27 ± 14.46 in Group A compared to 53.75 ± 12.64 in Group B, and this difference was statistically significant ($Z = -6.030$, $p < 0.001$). Similarly, psychological health scores were lower in Group A (34.78 ± 16.78) than in Group B (54.60 ± 15.38), with the difference reaching statistical significance ($Z = -5.359$, $p < 0.001$).

For the social relation domain, parents of children with cerebral palsy reported a mean score of 25.13 ± 17.19, markedly lower than the mean of 50.71 ± 10.14 observed in Group B, and the difference was statistically significant ($Z = -6.590$, $p < 0.001$).

In the environment domain, Group A had a mean score of 34.51 ± 10.93 compared to 54.25 ± 9.22 in Group B. This difference was also highly significant ($Z = -7.725$, $p < 0.001$).

Overall, parents of children with cerebral palsy reported significantly poorer QOL across all four domains of the WHO-BREF scale compared to parents of normal children.

Figure 2: Bar Graph Showing Comparison of QOL in Parents Using WHO BREF Scale



DISCUSSION

This study aimed to assess the quality of life (QOL) of parents of children with cerebral palsy (CP) and compare it to that of parents of typically developing children using the WHOQOL-BREF scale. The findings indicated that parents of children with cerebral palsy exhibited significantly lower quality of life scores across all four domains: physical health, mental health, social relationships, and environmental factors. The findings corroborate previous studies that highlight the complex challenges encountered by caregivers of children with cerebral palsy, who experience considerable mental, emotional, and physical hardships that detrimentally impact their quality of life.(34)

In the present study, caregivers of children with CP (Group A) and those of typically developing children (Group B) were comparable in terms of age, education, occupation, family composition, and relationship with the child, with no statistically significant differences. The mean caregiver age was in the late thirties, consistent with previous studies showing that parents of children with CP are typically in their third or fourth decade of life, balancing caregiving with work and family responsibilities (26,34).

Maternal caregivers predominated in both groups, reflecting global evidence that mothers disproportionately assume daily caregiving responsibilities, while fathers often provide financial support (35,36). Most caregivers were housewives, highlighting the career compromises associated with full-time caregiving demands, as also reported in studies from low- and middle-income countries (LMICs) (28).

Education levels were varied, though a considerable proportion of caregivers had completed secondary or higher education. While higher education has been associated with greater awareness and coping skills, studies suggest that even educated mothers in LMICs may face barriers due to cultural expectations and inadequate support systems (13).

Time devoted to caregiving was significantly higher in the CP group, averaging 11 hours per day compared to 5 hours in controls. This finding aligns with earlier research where parents of children with CP, particularly those with higher GMFCS levels, reported caregiving as a near full-time responsibility (8,37). Extended caregiving hours contribute to physical exhaustion, reduced social participation, and heightened risk of psychological distress (9).

The mean age of children was similar across groups. Within the CP group, spastic diplegia was the most common type, and nearly one-third of children were at GMFCS level III, consistent with epidemiological trends reported in other Indian and global studies (4,38).

Physical Health Domain

The physical health scores were significantly lower in the CP group (34.27 ± 14.46) compared with controls (53.75 ± 12.64). This difference is probably because caregiving is physically demanding and often involves tasks like lifting, moving, and helping the child with mobility, feeding, and daily hygiene. Over time, these repetitive and strenuous tasks contribute to musculoskeletal pain, fatigue, and poor sleep quality among caregivers, particularly mothers who predominantly shoulder caregiving responsibilities (39,40). Similar findings were reported by Raina et al. (8), who noted significantly higher rates of chronic physical problems among parents of children with disabilities compared to population norms. Thus, diminished physical health is both a direct consequence of the caregiving role and an indirect outcome of reduced time for self-care and health-seeking behaviors.

Psychological Health Domain

Psychological health was also significantly compromised in Group A (34.78 ± 16.78 vs. 54.60 ± 15.38 in controls). High levels of stress, anxiety, and depressive symptoms have been widely documented among parents of children with CP (28,41). The emotional burden stems not only from the day-to-day caregiving demands but also from long-term uncertainties regarding the child's prognosis, educational prospects, and future independence. Additionally, financial strain, marital stress, and social stigma may exacerbate psychological distress. A study by Park and Nam emphasized that the time burden of caregiving was directly associated with caregiver depression, suggesting that prolonged caregiving without adequate respite significantly erodes psychological well-being.(29)

Social Relationships Domain

The most profound disparity in this study was observed in the social relationship domain, where parents of children with CP scored nearly half of the control group (25.13 ± 17.19 vs. 50.71 ± 10.14). Social isolation is a common theme in caregiving literature, as parents often withdraw from social interactions due to time constraints, financial limitations, and lack of supportive childcare options. Furthermore, stigma and societal misconceptions about disability may lead to reduced social acceptance and exclusion from community activities (5,11). This loss of social connectedness can further aggravate psychological strain and reduce overall life satisfaction. Importantly, reduced social participation has a cyclical effect: caregivers deprived of social support may find it harder to cope with stress, thereby worsening both psychological and physical health outcomes.

Environment Domain

Environmental quality of life was also significantly poorer among parents of children with CP (34.51 ± 10.93) compared with controls (54.25 ± 9.22). Environmental challenges include financial difficulties, limited access to healthcare and rehabilitation services, inadequate community support systems, and poor infrastructure for accessibility (42,43). In resource-constrained settings, the economic burden of therapy, assistive devices, and medical interventions can be overwhelming for families, especially when one parent (usually the mother) is unable to engage in paid employment due to caregiving demands. Moreover, transportation difficulties, lack of inclusive schools, and limited social welfare benefits compound the environmental stressors experienced by these families.

The stark contrast in QoL scores compared with neurotypical caregivers underscores the unique caregiving burden in CP, which extends beyond typical parenting stressors. Similar comparative findings have been reported in Canadian, Turkish, and Middle Eastern contexts, suggesting the universality of this phenomenon.(13,30,34)

Influence of Demographic Factors

Demographic characteristics also play a pivotal role in shaping QOL outcomes. In this study, the majority of caregivers were in the age range of 31–40 years, a period often associated with balancing multiple roles, including parenting, household responsibilities, and, in some cases, employment. Mothers constituted the majority of caregivers, consistent with evidence from both high- and low-income countries that caregiving responsibilities disproportionately fall on women (11,41). Gendered caregiving not only intensifies physical and psychological burden but also limits opportunities for social and economic participation. In addition, the severity of the child's condition and the lack of institutional support services may exacerbate caregiver strain, as reported in earlier studies (34,40).

Implications for Practice and Policy

The present study demonstrated that parents of children with CP experience significantly poorer quality of life across all domains compared with parents of typically developing children. These findings are consistent with prior research and highlight the complex interplay of physical, psychological, social, and environmental challenges that caregivers face. The findings highlight the urgent need for interventions aimed at improving the QOL of caregivers of children with CP. Multidisciplinary approaches should include caregiver-focused physiotherapy programs to prevent musculoskeletal problems, counselling and stress management services to address psychological health, community-based support groups to enhance social connectedness, and policy initiatives to improve accessibility and financial assistance. Several studies have shown that caregiver training, respite care, and social support networks significantly reduce stress and improve overall caregiver well-being (8,11). As this was cross-sectional design it limits causal inference. The use of self-reported measures may introduce bias. Larger, multicenter longitudinal studies are recommended.

CONCLUSION

Caregivers of children with cerebral palsy report markedly diminished quality of life across physical, psychological, social, and environmental domains in comparison to caregivers of neurotypical children. This highlights the pressing necessity for multifaceted interventions to enhance caregiver well-being and avert prolonged detrimental health consequences.

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