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Original Article

EXPLORING THE QUALITY OF LIFE OF PARENTS AND SIBLINGS OF CHILDREN WITH CEREBRAL PALSY: IMPLICATIONS FOR CAREGIVING AND SUPPORT

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ABSTRACT

Objective: This study aimed to explore the quality of life (QOL) of parents and siblings of children with cerebral palsy (CP) and its implications for caregiving and support.

Methods: A hospital-based cross-sectional descriptive study was conducted in the Department of Pediatrics, S. P. M. C. H. I. Hospital, SMS Medical College, Jaipur, India, from March 2021 to December 2021. Parents and siblings of children with CP, aged 2-12 y, were enrolled. The World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire was used to assess QOL. Data analysis was performed using descriptive statistics and SPSS software.

Results: The study included 100 parents and siblings of children with CP. Most children had normal birth weight and were born at term. Spastic quadriplegia was the most common type of CP observed. More than half of the children had other medical conditions, with epilepsy being the most prevalent. WHO-QOL BREF scores were low across all domains. Physical domain was the most affected (9.97±2.15), followed by Social interaction domain (10.48±2.32) and psychological domain (10.83±2.26) and Environment domain (11±2.23). The age and gender of the child, severity of disability, education of caretakers, family type, socioeconomic status, chronic illness did not significantly impact the QOL of caregivers. Caregivers with impaired functional status reported lower QOL scores. Meeting scheduled appointments positively influenced caregivers' physical and environmental domain scores.

Conclusion: The caregivers of children with CP experience lower quality of life and high levels of stress. If sustained over time it can affect family dynamics and quality of care provided to such children with CP. The implications of these findings can guide the development of targeted interventions and support programs for caregivers of children with CP.

Keywords: Cerebral palsy, Quality of life, Caregivers, Siblings, Support, Intervention

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INTRODUCTION

Cerebral palsy (CP) is a non-progressive neurological disorder that permanently affects body movements and muscle coordination, with a prevalence rate of 2.83 per 1000 children in the age group of 0 to 19 y. In India, it stands as one of the leading causes of disability [1]. CP is characterized by impaired movement and posture due to defects or injuries to the developing brain. The condition's impact is further compounded by associated disabilities such as epilepsy, learning disabilities, behavioural and emotional problems, cognitive impairment, chronic pain, speech and visual impairments, and gastrointestinal and feeding difficulties [2, 3]. In addition to physical limitations, children with CP often require significant assistance with basic self-care functions such as feeding, dressing, bathing, and mobility. Consequently, these children are frequently confined to their homes, leading to restricted participation in daily activities.

Raising a child with a disability presents unexpected challenges and places substantial demands on caregivers. Care giving for a physically challenged child becomes a full-time job that can result in stress, strain on marital relationships, limited social interactions, reduced recreational time, and neglect of personal appearance [4]. Caregivers of children with CP commonly experience anxiety, social stigma, and a lack of social support. Unfortunately, caregivers often find themselves thrust into this demanding situation without prior preparation [5].

Caregivers' quality of life (QOL) is influenced by a combination of demographic factors and the child's disability. QOL, as defined by the World Health Organization, encompasses an individual's perception of their position in life within the context of culture, values, goals, expectations, standards, and concerns. It is a multidimensional concept that includes physical health, psychological state, independence, social relationships, personal beliefs, and the environment [6]. Assessing QOL is crucial in medical practice for improving the doctor-patient relationship, evaluating treatment effectiveness, assessing health services, conducting research, and informing policy-making. QOL holds relevance for chronic and impairing conditions such as cerebral palsy, intellectual disability, and autistic spectrum disorder [6].

Parents of children with developmental disabilities often face heightened stress, impaired mental health, feelings of devaluation, self-blame, and physical exhaustion [7]. The level of impairment in the QOL experienced by families caring for children with these severe chronic conditions is influenced by a complex interplay of environmental and genetic factors, including socioeconomic status, social support, parental and child characteristics, and coping strategies [8]. Studies have shown that higher levels of behaviour problems in children with cerebral palsy contribute to greater deterioration in their caregivers' psychological and physical health [9]. Additionally, research in Western countries indicates that the QOL of parents caring for children with developmental disorders is closely linked to the well-being and progress of their children [4, 10].

The impact of CP is not limited to the child but is extended to the caregivers of the child. This study aims to enhance our understanding of the QOL experienced by caregivers of children with cerebral palsy and determine the factors which affect their QOL, which is useful in planning interventions to improve caregiver well-being.

MATERIALS AND METHODS

Study place

The study was conducted in the Department of Paediatrics, S. P. M. C. H. I. Hospital, SMS Medical College, Jaipur.

Study period

From Mar 2021-Dec 2021.

Study design

This was a hospital-based cross-sectional descriptive questionnaire-based study.

Study population

Parents and siblings of children with cerebral palsy between 2-12 y of age attending pediatric OPD or Rehabilitation services with a voluntary willingness to participate in the study were enrolled.

Statistical analysis

Statistical analysis was done with descriptive statistics using SPSS version 10. The WHO-QOL data was analyzed using an SPSS syntax that automatically checks, re-codes data and computes the domain scores.

Sample size

The sample size is calculated at a 95% confidence level, expecting 70% of the parents to report QOL as neither good nor poor as per the reference article. At a 10% absolute allowance, the required sample size was 100 parents and siblings of a Cerebral palsy child.

Inclusion criteria

Parents and siblings (>8 y), belonging to families with an already diagnosed cerebral palsy (CP) child aged 2 to 12 y were considered eligible for participation. Only the individuals who had been consistently attending pediatric Outpatient Department (OPD) or Child Development Center (CDC) services over a continuous 3-month period were included as potential subjects. Participation was limited to those who had provided their explicit consent to take part in the study, ensuring a basis of voluntary and informed involvement.

Exclusion criteria

Parents and siblings of children diagnosed with cerebral palsy (CP) who also had comorbidities such as ADHD or autism were considered ineligible for participation. Additionally, individuals with acute medical illnesses were also excluded to avoid potential influences on the research outcomes.

Data collection

The semi-structured questionnaire consisted of the personal information profile and demographic details of parents, siblings, and affected children, thorough clinical assessment of the child, including GMFCS (gross motor function classification system) of CP child, associated co-morbidities in CP children. World Health Organization Quality of Life-BREF (WHOQOLBREF-) Questionnaire [6] was used to assess the quality of life of caregivers. It consists of 26 questions divided into four domains: physical, psychological, social, and environment. Each question was assigned an appropriate number of points from 1 to 5 (1=very dissatisfied to 5=very satisfied). Domain scores were scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain was used to calculate the domain score. The interpretation was done as per the specification in the WHOQOL-BREF questionnaire. Stress level was measured using a perceived stress scale [11]. Care-giving process was assessed by the availability of adequate healthcare resources, physiotherapy and ability to meet up with the scheduled appointments at health care facility.

RESULTS

In the current study, 100 caregivers of children with CP were enrolled. Half of the caregivers were aged between 30-39 y (51%) and one fourth (28%) were aged below 20 y. Fathers were the most common caregiver of children with cerebral palsy (44%), followed by mothers (29%) and siblings (27%). Nearly half of the caregivers were Graduate (47%), while 17% were illiterate. Only 42% of the caregivers had adequate knowledge about Cerebral palsy. Most of the caregivers had no chronic illness, while 13% of the caregivers had chronic illness.

Table 1: General characteristics of caregiver

		N	Percentage (of 100)
Relation with child	Father	44	44
	Mother	29	29
	Sibling	27	27
Age	<20 y	28	28
	20-29 y	16	16
	30-39 y	51	51
	40-49 y	5	5
Education	Illiterate	17	17
	Upto 10th	13	13
	Upto 12th	23	23
	Graduate/PG	47	47
Knowledge About CP	Yes	42	42
	No	58	58
Any chronic illness	Yes	13	13
	No	87	87
Socio economic status	Lower class	45	45
	Middle class	51	51
	Upper class	4	4

Table 2: Demographic and clinical characteristics child with cerebral palsy

Characteristic	Type	N	Percentage (of 100)
Age group(years)	<5 y	31	31
	5-9 y	50	50
	≥10 y	19	19
Gender	Male	63	63
	Female	37	37
Birthweight	LBW	18	18
	NBW	82	82
Gestational age at birth	Preterm	13	13
	Term	87	87

Characteristic	Type	N	Percentage (of 100)
Type of cerebral palsy	Ataxic	1	1
	Dyskinetic	12	12
	Mixed	6	6
	Spastic diplegia	27	27
	Spastic hemiplegia	13	13
	Spastic quadriplegia	41	41
Associated Comorbidity	Epilepsy	27	27
	Haemophilia	2	2
	Hearing loss	4	4
	Infantile spasm	3	3
	ITP	3	3
	Intellectual disability	1	1
	Movement disorder	4	4
	Vision impairment	7	7
	No	49	49
GMFCS	level 1	5	5
	Level 2	15	15
	level 3	35	35
	Level 4	23	23
	Level 5	22	22

Among the children with cerebral palsy, half (50%) were aged 5–9 y. Male to female ratio was found to be 1.7:1. Only 13% of the children were born prematurely and 18% were low birth weight. Spastic quadriplegia (41%) was the most prevalent kind of cerebral palsy in children, followed by spastic diplegia (27%), spastic hemiplegia (13%), and dyskinetic (12%). About half of the children with cerebral palsy had other associated morbidities, with epilepsy being the most prevalent (27%). Evaluation of motor function using GMFCS scale revealed that 45% of the children had severe restrictions in mobility (level 4 and 5) and nearly one-third (35%) walked with the use of hand-held mobility devices (level 3).

Table 3: WHO-QOL BREF domain scores of caregivers

Domain	WHO-QOL BREF scores (mean±SD)	Range
Physical	9.97±2.15	5–16
Psychological	10.83±2.26	7–17
Social	10.48±2.32	6–16
Environment	11±2.23	6–17

Quality of life of caregivers was assessed using WHO-QOLBREF. Scores were low across all domains. Physical domain was the most affected, with a score of 9.97±2.15, followed by Social domain (10.48±2.32) and psychological domain (10.83±2.26). Environment domain was least affected, with a score of 11±2.23.

Table 4: WHO-QOL BREF Domain scores in relation to characteristics of affected children

		WHO-QOL BREF domain scores			
		Physical	Psychological	Social	Environment
Age group (years)	<5 y	9.87±1.5	11±1.98	10.19±2.24	11.19±2.21
	5-9 y	10.02±2.39	10.74±2.37	10.6±2.37	11.06±2.35
	≥10 y	10±2.49	10.79±2.49	10.63±2.39	10.53±1.93
	Pvalue	0.954	0.880	0.713	0.572
Gender	Male	9.9±2.01	10.86±2.15	10.33±2.14	10.84±2.03
	Female	10.08±2.4	10.78±2.46	10.73±2.61	11.27±2.52
	Pvalue	0.695	0.876	0.412	0.354
Associated Comorbidity	Yes	9.51±1.94	10.25±2.13	10.22±2.47	10.61±2.3
	No	10.45±2.27	11.43±2.25	10.76±2.15	11.41±2.09
	Pvalue	0.028	0.009	0.247	0.072
GMFCS	level 1	9.2±0.84	10.6±1.67	9.4±1.52	11±1.41
	Level 2	10±1.77	10.53±0.99	10.73±1.71	10.8±1.52
	level 3	10.4±2.51	11.51±2.42	10.77±2.58	11.31±2.79
	Level 4	10.26±1.96	11±2.11	10.7±2.03	11.48±1.73
	Level 5	9.14±2.03	9.82±2.61	9.86±2.64	10.14±2.1
	Pvalue	0.219	0.087	0.475	0.270

WHOQOL domain scores were low in all age groups and both genders. Physical and social domain score were minimum in children below 5 y of age and male gender. However, the association was not found to be significant (p>0.05). Physical and psychological domain score was found to be significantly less among caregivers of children with the presence of other comorbidities as compared to those without. When correlated with the level of motor disability, the physical, psychological, and environmental domain scores were found to be lowest among caregivers of children with the highest physical impairments (GMFCS level 5).

Table 5: WHO-QOL BREF domain scores in relation to characteristics of caregivers

		WHO-QOL BREF domain scores			
		Physical	**Psychological**	**Social**	**Environment**
Age	<20 y	11.25±2.65	12.04±2.53	11.64±2.6	11.96±2.4
	20-29 y	9.25±1.57	10.75±2.02	9.25±1.69	10.69±1.66
	30-39 y	9.53±1.59	10.25±1.87	10.31±2.12	10.71±2.09
	40-49 y	9.6±3.21	10.2±3.03	9.6±1.95	9.6±2.88
	Pvalue	0.002	0.007	0.005	0.035
Education	Illiterate	9.41±1.54	10.82±2.21	9.88±2.12	10.41±1.91
	Upto 10th	10.23±3.49	11±2.74	10.46±2.47	10.85±3.08
	Upto 12th	10.96±2.33	11.74±2.58	11.57±2.78	11.96±2.27
	Graduate/PG	9.62±1.62	10.34±1.87	10.17±1.98	10.79±1.96
	Pvalue	0.057	0.110	0.070	0.113
Knowledge About CP	Yes	9.98±1.89	10.64±2.24	10.31±2.05	10.71±1.9
	No	9.97±2.34	10.97±2.29	10.6±2.51	11.21±2.43
	Pvalue	0.981	0.484	0.535	0.277
Any chronic illness	Yes	9.92±2.81	11±2.92	10.62±2.22	11±2.31
	No	9.98±2.06	10.8±2.17	10.46±2.35	11±2.23
	Pvalue	0.933	0.773	0.823	1.000
Socio economic status	Lower class	10.02±2.32	10.89±2.47	10.36±2.3	10.64±2.25
	Middle class	9.94±2.1	10.84±2.15	10.57±2.36	11.37±2.23
	Upper class	9.75±0.5	10±1.15	10.75±2.63	10.25±1.26
	Pvalue	0.963	0.755	0.881	0.221
Scheduled appointments met	Yes	10.33±2.08	10.97±2.22	10.79±2.21	11.34±2.19
	No	9.24±2.14	10.55±2.35	9.85±2.45	10.3±2.16
	Pvalue	0.017	0.380	0.056	0.027

The score of all four domains of QOL were highest among caregivers aged<20 y, indicating better QOL. In psychological and environmental domain, the scores kept falling with increasing age of caregivers. Significant association was seen in between age of caretakers and all the domains of QOL ($p<0.05$). Physical and psychological domain scores were lowest among graduate caretakers, while social and environmental domain scores were lowest among illiterate caretakers. Physical, psychological, and environmental domain scores were lowest among caretakers from upper socioeconomic status, while social domain scores were lowest among caretakers from lower socio-economic status. All the four domain scores were found to be better among caretakers who met scheduled appointments for the child with CP as compared to those who could not.

Most of the caretakers had moderate perceived stress (76%), while 12% had high perceived stress and only 12% had low perceived stress. All the WHO QOL domain scores were highest among patients with low perceived stress. Significant association was found between physical ($p=0.006$) and psychological scores ($p<0.001$) and perceived stress of caretakers.

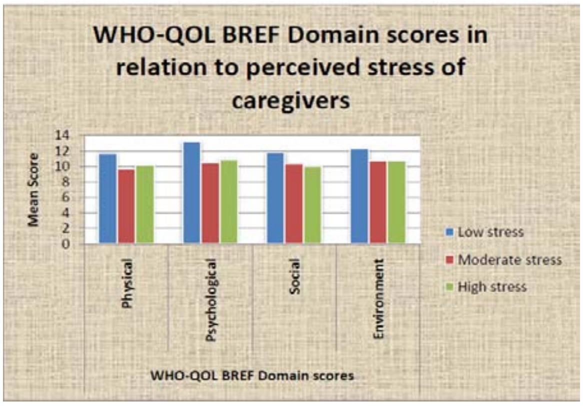

Fig. 1: WHO-QQL BREF domain scores

DISCUSSION

This study sought to better understand the quality of life (QOL) of parents and siblings of children with cerebral palsy (CP) and its implications for caregiving and support. The physical, emotional, and social health of parents, as well as their parenting techniques, are intricately related to the health and well-being of their children. The findings of our study revealed several important insights into the challenges faced by caregivers and the impact on their QOL. The study included 100 parents and siblings of children with CP. Most of the children had normal birth weight and were born on time. Spastic quadriplegia was the most common type of CP observed, and more than half of the children had other medical conditions, with epilepsy being the most prevalent. These findings align with previous research, which has consistently shown a high prevalence of spastic quadriplegia and comorbidities in children with CP [12].

One of the key findings of the study was that caregivers reported low QOL scores across all domains, with the physical domain being the most affected. This is consistent with previous researchers that have shown the significant impact of caregiving for a child with CP on the physical health and well-being of parents, though the most affected domain may vary [13, 14]. Caregiving for a child with CP often involves extensive physical demands, such as lifting, transferring, and aiding with daily activities, which can take a toll on the caregiver's physical health [15].

We found that the parents who had children with impaired functional status, according to GMFCS had lower mean scores in physical, psychological, and environmental domains. Interestingly, the severity of the child's disability as per GMFCS did not significantly impact the QOL of caregivers. This suggests that other factors, such as social support, coping strategies, and the availability of resources, may play a more significant role in determining the well-being of caregivers. This finding highlights the need for comprehensive support services and interventions to improve caregiver well-being, regardless of the severity of the child's disability.

The study also found that caregivers with impaired functional status reported lower QOL scores. This emphasizes the importance of considering the caregiver's own health and functional abilities when designing support programs and interventions. Providing resources and assistance to help caregivers maintain their own physical and mental well-being is crucial in ensuring optimal care for the child with CP [4].

Another noteworthy finding was that the age and of the child did not significantly affect caregivers' QOL scores. This suggests that the challenges and demands of caregiving persist throughout the child's developmental stages and that ongoing support and interventions are needed regardless of the child's age [10, 16]. We also observed a decline in the QOL of caregivers in all four domains as age of the caregiver increased.

Furthermore, meeting scheduled appointments positively influenced caregivers' physical and environmental domain scores. This finding highlights the importance of access to healthcare services and the role of healthcare providers in supporting caregivers. Timely and regular medical care, as well as clear communication and collaboration with healthcare professionals, can help alleviate some of the burden on caregivers and improve their QOL. A significant factor causing stress for parents is being aware of existing opportunities in treatment and rehabilitation while at the same time not having access to these opportunities due to economic barriers [17].

Overall, the study underscores the significant impact of caring for a child with CP on the QOL of parents and siblings. The findings of this study align with previous research in the field. Several studies have highlighted the challenges faced by parents of children with CP and their impact on QOL. It emphasizes the need for comprehensive support services and interventions to improve caregiver well-being. Understanding the factors influencing QOL can guide the development of targeted interventions and support programs for caregivers of children with CP [18].

Furthermore, studies have shown that the QOL of parents caring for children with developmental disorders is closely linked to the well-being and progress of their children. For example, a study by Raina *et al.* highlighted the interplay between the QOL of parents and the health and well-being of children with CP [4].

So, our study adds to the growing body of literature on the QOL of parents and siblings of children with CP. The findings highlight the significant impact of care giving on the physical, psychological, and social well-being of caregivers. The study emphasizes the need for comprehensive support services, including access to healthcare, social support, and interventions to improve caregiver well-being. By understanding the factors influencing QOL, healthcare professionals and policymakers can develop targeted interventions and support programs to address the unique needs of caregivers of children with CP.

CONCLUSION

The carers of children with cerebral palsy scored poorly in every aspect of quality of life. The most affected domains were the Physical followed by Social. The existence of other comorbidities in children with CP made the quality of life even worse. Caretakers' quality of life was higher when they adhered to medical treatment and kept appointments as scheduled. Young caregivers had better QOL. Caregivers' education, knowledge about CP, socioeconomic status and presence of any chronic ailment did not significantly affect their QOL. Future research is needed to identify other factors affecting the quality of life that are not covered in the present research and the perspective of caregivers other than mothers.

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AUTHORS CONTRIBUTIONS

All the authors have contributed equally.

CONFLICTS OF INTERESTS

Declared none

REFERENCES

1. Smith JA. Management of post-burn hand contractures. Plast Surg. 2020;45(2):123-36.
2. Johnson SR. Functional outcomes following plantar skin graft for hand burn contractures. Burns Wound Heal. 2019;32(4):287-95.
3. Brown DP. Reconstructive surgery for hand burn contractures: a comparative study of grafting techniques. J Reconstr Surg. 2018;50(3):212-25.
4. Miller ER. Glabrous skin grafting for palmar hand burn contractures: a review of cases. Hand Surg J. 2017;28(1):45-56.
5. Adams RL. Harvesting plantar skin grafts for hand contracture reconstruction: A case series. J Burn Care Res. 2016;38(5):401-15.
6. Wilson JM. Functional and cosmetic outcomes of de-epithelized plantar skin graft in hand burn contractures. Plast Reconstr Surg. 2015;42(6):567-78.
7. Robinson MA. Management of postburn hand contractures: a retrospective analysis. J Hand Surg. 2014;48(7):620-32.
8. Okurowska Zawada B, Kułak W, Wojtkowski J, Sienkiewicz D, Paszko Patej G. Quality of life of parents of children with cerebral palsy. Prog Health Sci. 2011;1(1).
9. Arnaud C, Smith R, Johnson L. Quality of life in parents of children with cerebral palsy: a systematic review. J Dev Phys Disabil. 2011;23(6):469-85.