

The quality of life of primary caretakers of children with cerebral palsy

Alpana Kondekar, Qudsiya Ansari, Hrishikesh Ghatol

Department of Pediatrics, TN Medical College and BYL Nair Hospital, Mumbai Central, Mumbai, Maharashtra, India

ABSTRACT

Background: Cerebral palsy (CP) is a heterogeneous group of disorder affecting the development of movement and posture, which is permanent nonprogressive. Previous studies in different regions have shown links between caregivers' mental health and children's well-being. However, the lack of such detailed research for the caretakers of children with CP and correlation of quality of life affected the type and severity of the condition; this necessitates the development of a new study to assess caregivers' quality of life. **Aim:** Quality of life among caregivers of disabled children is an important concern in healthcare. We aim to evaluate the quality of life among caregivers of children with CP and to assess the factors affecting the caregivers' quality of life, namely, age, gender, type, and gross motor function in children with CP. **Methodology:** This was a cross-sectional observational study, conducted over a period of 6 months. It included the caregivers of children with CP at a tertiary care hospital of Mumbai. Data were collected using the WHO BREF questionnaire. The children were divided into two groups (2 to 7 years and 7 to 12 years). The qualities of life of the caretakers of these two groups were compared in four domains, namely, physical, psychological, social, and environmental. **Results:** The study included 50 participants. Mothers (80%) and fathers (10%) were the primary caregivers. Caretakers of the children with cerebral palsy showed significant affected quality of life as calculated from WHO QOL BREF score in both age groups (2-7 and 7-12 years) and in all domains. Overall, the most affected domain in our study was of psychological health and the least affected domain was of the environmental domain. **Conclusion:** This study provides a snapshot of the impact of having a child with cerebral palsy on the lives of the caregivers. Most of the caregivers in the study were mothers, and quality of life was affected in all domains mainly in psychological and physical domains. The study showed that there is a need for interventions in caregivers which can have an indirect impact on the children with CP.

Keywords: Caretakers, cerebral palsy, quality of life

Introduction

Cerebral palsy (CP) is the term used to describe individuals with a movement disorder resulting from nonprogressive disturbance to the developing brain.^[1] CP is the most common motor disability in childhood.^[2] The motor disorders of CP are associated with disturbances of sensation, perception, communication and behavior, epilepsy, and secondary musculoskeletal problems.^[3]

Address for correspondence: Dr. Qudsiya Ansari, Topiwala National Medical College, Nair Hospital, Mumbai Central, Mumbai - 400 008, Maharashtra, India.
E-mail: ansari.qudsiya31@gmail.com

Received: 13-02-2024

Revised: 08-04-2024

Accepted: 29-04-2024

Published: 18-10-2024

The worldwide prevalence of CP ranges from 1.5 to more than 4 per 1000 live births or children of a defined age range.^[4] In India, it is estimated at around 3 cases per 1000 live births; however, being a developing country, the actual figure may be much higher than probable figures. The prevalence of CP has increased as a result of the increased survival of very premature infants. Perinatal risk factors for CP include intrauterine infections, teratogenic drug exposures, placental complications, multiple births, and maternal conditions such as mental retardation, seizures, or hyperthyroidism and intrauterine exposure to maternal infection.^[5] There are about 25 lakhs of CP children in India as per the last statistical information. The most widely utilized classification system for the severity of motor limitations

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

How to cite this article: Kondekar A, Ansari Q, Ghatol H. The quality of life of primary caretakers of children with cerebral palsy. J Family Med Prim Care 2024;13:4457-61.

Access this article online

Quick Response Code:



Website:
<http://journals.lww.com/JFMPC>

DOI:
10.4103/jfmpe.jfmpe_223_24

in children with CP is the gross motor function classification system (GMFCS).^[6] Although CP is diagnosed in an individual, when he or she is a child, the whole family's daily routine can be changed because of the disease.^[3]

The 1956-dated classification system issued by the American Cerebral Palsy Academy is still the commonly utilized system of today: Four motor types have been classified as spastic, dyskinetic, ataxic, and hypotonic.^[7,8] Irrespective of the type of CP, all affected children require special attention and care. The special care needed by the child depends on many factors like severity of the disease, overall condition of health status, nutrition, functional capacity, and financial level of the family.^[9] There was a need for more studies pertaining to QOL information relating to the caregivers of children with CP in this region and to assess the factors affecting the caregivers' quality of life, namely, age, gender, type, and gross motor function (by Gross Motor Functional Classification System) in children with CP.

Material and Methods

This was a cross-sectional observational type of study conducted over a period of 6 months, from July 2019 to December 2019, at a tertiary care center of Mumbai. As the prevalence of CP in India is 2 to 3 children per 1000 live birth, by the sample size formula $\text{sample size} = 4PQ/D^2$, where P is prevalence, Q is 100-P, D is allowable error, and along with that after considering duration of our study and pediatric OPD attendance of CP children, our sample size calculated as 50. All primary caretakers of the child suffering from CP between 2 years and 12 years were included. A primary caregiver refers to the parent who has the greatest responsibility for the daily care and rearing of a child. Caregivers having other major factors besides CP which were likely to hamper caregivers' quality of life like recent onset family dysfunction, acute financial crisis, and marital dispute were excluded from the study.

Methodology

This study aims to determine the quality of life of primary caregivers of children with CP. Quality of life of the primary caregiver of a child with CP was assessed with the WHO BREF questionnaire (Hindi and English Version). The WHO QOL BREF questionnaire is tested in different parts of the world and had been certified to use for assessing quality of life in people. WHO is having open access policy to use all publications published by WHO, and the same has been confirmed from E-mail reply from WHO dated 12-07-2019 regarding my permission request Enquiry ID 293065. Caregivers of children suffering from CP between 2 years and 12 years were recruited for the study. A brief explanation of the entire study process was done using parent information sheets. Written information consent was taken from the parent/caregiver.

General details of the caregiver were taken along with assessment of the child, for example, any history of antenatal complications

in the mother, history of birth insult, and postnatal history including NICU stay. In our study, quality of life of the caregiver was studied in four domains, mainly physical, psychological, social, and environmental. The children were divided into two groups (2–7 years and 7–12 years). The quality of life of the parents of these two groups will be compared in four domains, namely, physical, psychological, social, and environmental. Similarly, division was also done on the basis of gender and the quality of life of caretakers of male and female CP children will be compared in the same four domains of life. The range of gross motor function of CP children also impacts the life of children themselves and also the caregiver. Therefore, children were divided according to GMFC (Gross Motor Functional Classification) classification and quality of life of caregivers of children with different GMFC level classifications will be compared in four domains of life as stated before.

Study outcome and data analysis: The WHOQOL-BREF questionnaire is used to study the quality of life of the caregivers of the children with CP in different domains of life. The scores that we got according to their answers (called as raw scores) were converted into transformed scores using the table provided by WHO. Transformed scores less than 50 indicate a poor quality of life, while scores more than 50 indicate a good quality of life. Approval from the ethics committee [ethics committee for academic research project (ECARP)] had obtained on 07/03/2020.

Results

A total of 50 cases of CP were included in the present study, which was carried out in the Department of Pediatrics, Nair Hospital, Mumbai, during the period of July 2019 to January 2020. Cases were divided into two age groups, between 2 and 7 years and between 7 and 12 years, which were further divided into severity of motor function by GMFCS classification.

In the present study, quality of life of caretakers was found to be affected in all four domains as all the domains have scores less than 50. The worst affected domain was of psychological health; the next affected domain was of physical health. Social (37.32 domain score) and environmental domains (37.96 domain score) were less affected than psychological (35.2 domain score) and physical domains (35.8 domain score).

Out of total 50 cases, 40 primary care takers were mothers (80%) and 10 caretakers were fathers (20%). The QOL most affected seen with the mother was of the physical health domain (36.27) in contrast with the father, in which the most affected QOL was psychological (31.4 domain score). The other domain affected in the father next to the psychological domain was the social domain (score 31.8). In the mother, the affected domain next to physical health was of the psychological domain (36.37 domain score).

Out of 50 cases, based on motor function abilities of Cerebral Palsy (GMFCS), the total number of mild to moderately affected

CP children (GMFCS type 1 to 3) was 30 (60%) and severely affected children (GMFCS type 4 and 5) were 20 (40%). In this study, all the domains of the caretaker were found to be affected in both mild to moderate and severely hampered motor-functioned CP children. Among the caretakers of mild to moderately affected CP children, the worst affected domain was of psychological health (domain score 38.1) and the least affected domain was of environmental health (domain score 41.83). Among the caretakers of severely affected CP children, the worst affected domain was of social health (domain score 30.7) and the least affected domain was of environmental health [Table 1 and Graph 1].

Quality of life of caretakers is most affected in spastic diplegic CP and spastic quadriparetic CP. QOL is found to be least affected in ataxic CP [Table 2 and Graph 2].

Of the 50 cases, 32 participants (64%) were in the age group of 2–7 years and 18 participants (36%) were in the age group of 7–12 years. In the 2–7-year age group with mother as a primary caretaker, the worst affected domain was physical health (domain score 34) and the least affected domain was the environmental domain (domain score 38.8). With father as a primary caregiver, the worst affected domain was of environmental health (domain score 20.2) and the least affected domain was of physical health (28.8). In 7–12 years age group, with mother as a primary caretaker, the worst affected domain was of psychological health and the least affected domain was of social health. With father as a primary caretaker, the worst affected domain was the psychological domain (domain score 37.6) and the least affected

domain was of environmental health (domain score 49) [Table 3 summarization of all results]. Since the study was compared within the group only and overall the QOL was affected in general for the primary care taker within the group, the *P* value was not statistically significant. Control was mild to moderate versus severely affected motor function GMFCS classification-wise CP children caretakers, and in both groups, QOL was affected, and hence, *P* value was not significant in this study.

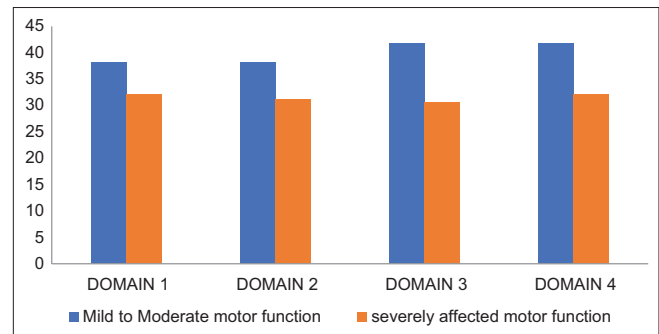
Discussion

In the present study, there were a total of 50 caretakers enrolled, out of which 40 were mothers and 10 were fathers of the CP children. A majority of the caregivers (32 caregivers, 64% of total) were enrolled in 2–7 years of age group category of CP children. 36% caregivers were enrolled in 7–12 years age group category. J Wu, J Zhang, and Y Hong studied the QOL of mothers and grandmothers of CP patients; it was found that quality of life was affected in mothers and grandmothers of the CP patients.^[10]

In our study, there were a total of 30 caregivers (60% of the total) in GMFCS type 1 to 3 of CP motor function classification-wise; 20 caregivers (40% of the total) were of severely affected GMFCS classification category of CP children. Among the caregivers of mild to moderately affected CP children (motor function GMFCS type 1 to 3), the most affected domain was of psychological health and the least affected domain was of

Table 1: Comparison of QOL of caretakers based on GMFCS motor function of cerebral palsy children

| Domains | Mild to moderate motor function (GMFCS 1 to 3) | Severely affected motor function (GMFCS 4 and 5) |
|--------------------------|--|--|
| Physical health (D1) | 38.26 | 32.1 |
| Psychological (D2) | 38.1 | 31.25 |
| Social relationship (D3) | 41.7 | 30.7 |
| Environment (D4) | 41.83 | 32.15 |



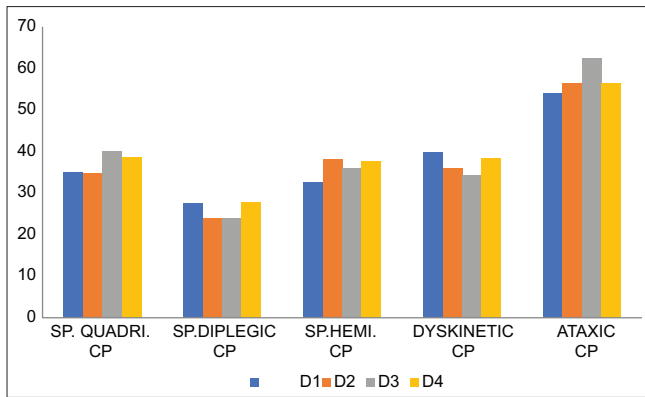
Graph 1: OL of caretakers based on GMFCS motor function of cerebral palsy children

Table 2: QOL of caretakers in different types of CP

| Domain | Spastic Quadri. CP | Spastic hemi. CP | Spastic Diplegic CP | Dyskinetic CP | Ataxic CP |
|--------------------------|--------------------|------------------|---------------------|---------------|-----------|
| Physical health (D1) | 35.04 | 32.6 | 27.6 | 39.75 | 54 |
| Psychological (D2) | 34.7 | 38 | 24 | 36 | 56.5 |
| Social relationship (D3) | 40.08 | 36 | 23.8 | 34.33 | 62.5 |
| Environment (D4) | 38.5 | 37.63 | 27.8 | 38.25 | 56.5 |

Table 3: Comparison of quality of life (WHOQOL-BREF) of primary caretakers with CP

| Domains | Average | Male | Female | GMFCS 1-3 | GMFCS 4 and 5 | 2-7 year age | 7-12 year age |
|---------------------|---------|-------|--------|-----------|---------------|--------------|---------------|
| Physical health | 35.8 | 36.27 | 33.9 | 38.26 | 32.1 | 35.3 | 36.6 |
| Psychological | 35.38 | 36.37 | 31.4 | 38.1 | 31.25 | 36.43 | 33.5 |
| Social relationship | 37.32 | 38.7 | 31.8 | 41.7 | 30.7 | 37.3 | 37.3 |
| Environment | 37.96 | 38.75 | 34.6 | 41.83 | 32.15 | 35.2 | 42.8 |



Graph 2: QOL of caretakers in different types of CP

environmental health. In caretakers of severely affected motor functions of CP children, the worst affected domain was the social domain and the least affected domain was of physical health. In 2017, Chang-Kyo Yun studied the relationship between the QOL of the caregiver and motor function of children with CP. 108 caregivers of CP children under 18 years were enrolled in the study, and short-form health survey (SF-36) was applied to assess the QOL of the caregivers of CP children. The study showed that the QOL of the caregivers was well correlated with the motor function of children with CP. It was found that QOL of the caregivers was more affected in both physical health and psychological health domains, especially of those caregivers of children with severely affected motor functions.^[11]

The study conducted by Fadwa M and S. Mohammed had a cross-sectional study to compare the quality of life of caregivers of CP children. 65 caregivers of CP children aged 4 to 18 were enrolled in the study. Caregivers' life was compared by QOL proforma developed by Sudanese institution, which measures the QOL based on mainly four domains – physical health, social health, support for care, and financial burden. The study concluded that social health domain and financial burden were more affected and QOL was found to be on the low as compared to average individuals in communities.^[12]

Overall, the most affected domain in our study was of psychological health and the least affected domain was the environmental domain. In mothers, the worst affected domain was of physical health, while in fathers, the psychological domain was found to be most affected. In both mothers and fathers, the least affected domain was of environmental health. In the study conducted by Chidimma J, Ahanotu O. from Nigeria, who studied QOL of caregivers of CP patients from the local population, QOL was found satisfactory among all domains of QOL BREF scale. Among the four different domains, physical and psychological domains were found to be affected more than environmental and social domains. 78 informal caregivers participated in that study.^[13] In the study conducted by Elise Davis and Elizabeth Waters, who studied the impact of caring for a child with CP on QOL of parents, in which total 37 caregivers were recruited (24 mothers and 13 fathers), it was found that there was

no major difference between the QOL of mother and fathers. Social and psychological domains were found to be more affected than physical and environmental domains.^[14] Amanda Azevedo, Breno Morais, and colleagues studied the factors influencing the quality of life of caregivers of CP children. Total 45 caregivers of the CP children were enrolled in the study. QOL of caregivers was calculated on the basis of WHO QOL BREF proforma. Association of gross motor function of the CP children and socioeconomic status of the caregivers were correlated with the QOL of the caregivers. It was found that quality of life of caregivers appears to be influenced by socioeconomic level and not by the level of motor function of children with CP.^[15]

In our study, caretakers of the children with CP showed significant affected quality of life as calculated from WHO QOL BREF score in both age groups (2–7 and 7–12 years) and in all domains. In 2–7 years of age group, the worst affected domain was of the environmental one and the social relationship domain was least affected. In 7–12 years of age group, the psychological domain was most affected and the environmental domain was least affected. While in mothers of 2–7 years of age group, physical health was found to be most affected, in fathers, the environmental health domain was most affected in 2–7 years of age group. In 7–12 years of age group, in both mothers and fathers, the most affected domain was the psychological health domain. Lim Yee and Chee Piau Wong studied the impact of CP on quality of life of caregivers of CP children in Malaysian population using Lifestyle Assessment Questionnaire–Cerebral Palsy (LAQ-CP). A total of 27 caregivers of CP children of age between 3 and 10 years were recruited in the study. A majority of caregivers of CP children (40%) were found to have affected quality of life mainly in social and psychological health-related domains.^[16]

A majority of the cases enrolled in our study are of spastic CP children, of which spastic quadriparetic CP children form the major bulk of the total cases (46% of the total cases enrolled). Quality of life is found to be most affected in cases of spastic diplegic CP and spastic quadriparetic CP. Quality of life was least affected in ataxic CP.

In the study conducted by Shiji Chalipat, Sudhir Malwade, and Geeta Karambelkar at D.Y. Patil Hospital Pune assessing the quality of life of parents of children with CP using WHO QOL BREF proforma, it was found that QOL of parents of CP children was affected in all domains, with predominant affection of the social domain followed by the psychological domain. 30 caregivers of children with CP between 2 and 12 years of age attending Pediatrics OPD were enrolled in the study.^[17] In the study conducted by Helena Strom and Margareta Kreuter in Cambodia to assess the quality of life of caretakers of children with CP, in which total 40 caretakers were enrolled in the study and quality of life of caregivers was calculated by using Comprehensive Quality of life Scale A5 (ComQOL-A5), it was found that three mainly affected domains of quality of life were health-related, material well-being, and emotional well-being.

Of these areas, QOL in the health domain demonstrates the lowest scores.^[18] A recent study by Farajzadeh A, Maroufizadeh S, and Amini M. on factors associated with quality of life among mothers of children with CP was conducted, aimed to identify the factors pertaining to the quality of life among the mothers of patients with CP; results indicated that depression, the burden of care, fatigue, and the type of CP could significantly predict QOL in these mothers.^[19]

Conclusion

This study provides a snapshot of the impact of having a child with CP on the lives of the caregivers. Most of the caregivers in the study were mothers, and quality of life was affected in all domains, mainly in psychological and physical domains. The study showed that there is a need for interventions in caregivers which can have an indirect impact on the children with CP. Future research should explore the role of rehabilitation workers, and institutions on QOL can bring more detailed and specific results which will be beneficial to plan intervention.

Acknowledgment

The authors thank, Dean of T.N. Medical College and BYL Nair Hospital for granting permission to publish this manuscript.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

References

1. Kliegman RM, Stanton BF, St Geme III JW, Schor NF. Encephalopathy. In: Kliegman RM, editor. Nelson Textbook of Pediatrics. 1st ed. New Delhi: Elsevier India; 2016. p. 2896.
2. Blair E, Watson L. Epidemiology of cerebral palsy. In: Seminars in Fetal and Neonatal Medicine. 11th ed. WB Saunders; 2006. p. 117-25.
3. Sankar C, Mundkur N. Cerebral palsy-definition, classification, etiology and early diagnosis. Indian J Pediatr 2005;72:865-8.
4. The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. Soc Sci Med 1995;41:1403-9.
5. Wu YW, Escobar GJ, Grether JK, Croen LA, Greene JD, Newman TB. Chorioamnionitis and cerebral palsy in term and near-term infants. J Am Med Assoc 2003;290:2677-84.
6. Waters E, Maher E, Salmon L, Reddihough D, Boyd R. Development of a condition-specific measure of quality of life for children with cerebral palsy: Empirical thematic data reported by parents and children. Child Care Health Dev 2005;31:127-35.
7. Dodd KJ, Imms C, Taylor NF. What is cerebral palsy? In: Imms C, Dodd KJ, editors. Physiotherapy and Occupational Therapy for People with Cerebral Palsy. 1st ed. London: British Library Cataloguing; 2010. p. 7-31.
8. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, *et al.* A report: The definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl 2007;109:8-14.
9. Tedla J, Asiri F, Reddy R, Gular K, Kakaraparthi V, Sangadala D, *et al.* Caregiver's quality of life among children with cerebral palsy in the kingdom of Saudi Arabia, and various influencing factors: A single cohort study. J Multidiscip Healthc 2023;16:3705-14.
10. Wu J, Zhang J, Hong J. QOL of primary caregivers of children with cerebral palsy: A comparison between mother and grandmother caregivers in Anhui province in China. Child Care Health Dev 2017;43:718-24.
11. Yun CK. Relationship between the quality of life of the caregiver and motor function of children with cerebral palsy. Phys Ther Rehabil Sci 2017;6:26-32.
12. Fadwa MS, Mutaz A. Quality of life of cerebral palsy patients and their caregiver. J Neurosci Rural Pract 2016;7:355-61.
13. Ahanotu CJ, Ibikunle PO, Hammed AI. Burden of caregiving, social support and quality of life of informal caregivers of patients with cerebral palsy. Turk J Kin 2018;4:58-64.
14. Davis E, Waters E. The impact of caring a child with cerebral palsy. Child Care Health Dev 2010;36:300.
15. Almeida KM, da Fonseca BM, Gomes AA, Oliveira MX. Factors influencing the quality of life of caregivers of cerebral palsy children. Fisioter Mov 2013;26:307-14.
16. Lim M, Wong CP. Impact of cerebral palsy on the quality of life in patients and their families. Neurol Asia 2009;14:27-33.
17. Chalipat S, Malwade SD, Karambelkar GR. Assessment of quality of life of parents of children with cerebral palsy. J Evid Based Med Health 2016;3:4673-7.
18. Strom H, Kreuter M, Rosberg S. Quality of life in caretakers of children with cerebral palsy in cambodia. J Trop Pediatr 2021;58. doi: 10.1093/tropej/fmr077.
19. Farajzadeh A, Maroufizadeh S, Amini M. Factors associated with quality of life among mothers of children with cerebral palsy. Int J Nurs Pract 2020;26:e12811.