

ASSESSMENT OF QUALITY OF LIFE OF PARENTS OF CHILDREN WITH CEREBRAL PALSY

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ABSTRACT**BACKGROUND**

Raising a child with chronic disability is stressful and demanding task which can affect the quality of life of the parent/caregiver adversely.

The aim of this study was to assess the quality of life of parents of children aged between 2-12 years with cerebral palsy.

MATERIALS AND METHODS

This was a cross sectional descriptive questionnaire based study, which included 30 parents of children with cerebral palsy between 2-12 years of age attending Paediatric OPD or Rehabilitation services. Interviews were conducted using a semi-structured questionnaire and quality of life was assessed using World Health Organization Quality of Life-BREF (WHOQOL-BREF-) Questionnaire-short version. Statistical analysis was done with descriptive statistics using SPSS version 10.

RESULTS

The mean score of the social domain of quality of life of caregivers was the lowest (9.33±1.49 SD) followed by psychological (18.23±1.50 SD). Seventy percent of parents reported their overall quality of life as neither good nor poor and 66.67% of parents were satisfied with their own health.

CONCLUSION

Quality of life of parents of children with CP was affected in all domains, with predominant affection of social domain. More than half of parents were satisfied with their own general health and they reported overall quality of life was neither good nor poor.

KEYWORDS

Cerebral palsy, Parents, Quality of life, Health satisfaction.

MeSH terms: Cerebral palsy, Parents, Quality of life.

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BACKGROUND

Quality of life (QOL) is an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their aims, expectations, standards and interests, conditioned by the environment.⁽¹⁾ Cerebral palsy (CP) is a non-progressive disorder of movement and posture, with a prevalence of 2.83 per 1000 children among the age group of 0 to 19 years. It is one of the most common causes of disability in India.⁽²⁾

AIMS AND OBJECTIVES

A child with CP suffers from several problems such as spastic paralysis, cognitive impairment, chronic pain, speech and visual impairment, and gastrointestinal and feeding problems.⁽³⁾ They also have limitations in self-care functions such as feeding, dressing, bathing, and mobility. Taking care of a physically challenged child is a full-time job with great demands, and it exerts a great stress on the caregiver. Unfortunately, this happens without prior preparation, and the caregivers find themselves suddenly in this demanding situation. This not only causes increased economic burden on the family and time spent on taking care of the affected child but also has impact on physical, psychological and social aspects of the quality of life of caregiver. The quality of life of caregivers should be studied thoroughly to improve the care of the affected children and overall health status of the family. India has got diverse population and different socioeconomic backgrounds along with significant differences in availability of health care facilities in urban and rural areas. These demographic factors along with patient's

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disability in turn affect the quality of life of caregivers. Thus this study was planned to help the improvement in the understanding of the quality of life of caregivers that can allow us to determine the extent of the problem. Several studies of this kind have been undertaken in western countries.^(4,5,6) but very few studies have been reported from India that assess the quality of life of caregivers having children with cerebral palsy.

MATERIAL AND METHODS

Study Location

This study was conducted at Dr. D. Y. Patil Medical College, Hospital Research Center Pimpri, Pune, Maharashtra, India.

Study Population

Thirty parents of children with cerebral palsy between 2-12 years of age attending Paediatric OPD or Rehabilitation services with voluntary willingness to participate in the study were enrolled.

Study Design

This was a cross sectional descriptive questionnaire based study.

Sampling and Data Collection

Institutional ethical committee clearance was obtained prior to commencement of study. 37 subjects with cerebral palsy visiting Paediatric OPD or Rehabilitation services consecutively during the 3 months period were identified as eligible subjects. Parents were explained about the study procedure and a written informed consent was obtained from 30 parents who were voluntarily willing to participate in the study. Four parents refused to participate and 3 parents were missed as they failed to turn up after they were sent to other OPD for referrals. The interviews were held in confidentiality in a separate room in the OPD which lasted on an average from 30-40 minutes. The semi-structured questionnaire consisted of two parts:

- i. The personal information profile along with demographic details of parents and affected children.
- ii. The World Health Organization Quality of Life-BREF (WHOQOL-BREF-) Questionnaire-short version.⁽⁷⁾ that was used to assess the quality of life. A thorough clinical assessment of affected children including functional status assessment using GMFCS (Gross Motor Function Classification System) - Expanded and Revised.⁽⁸⁾ was performed and associated co-morbidities were identified. It was ensured that the caregivers understood the questions and sufficient time was given for them to answer.

Standard definitions were used to define cerebral palsy, epilepsy, intellectual disability.^(9,10,11) Visual and hearing impairment were assessed by trained ophthalmologist and audiologist and confirmed by performing appropriate tests. Behavioural problems were assessed by the clinical psychologist. The socioeconomic status was assessed using Modified Kuppaswamy scale.⁽¹²⁾

Scoring

World Health Organization Quality of Life-BREF (WHOQOL-BREF-) Questionnaire-short version-consists of 26 questions divided into four domains:

A. Physical Health

General health assessment, pain and discomfort, dependence on medication and medical aids, energy and fatigue, sleep and rest, ability to work and perform daily living activities, mobility. Items 3,4,10,15,16,17 and 25 of the questionnaire represent satisfaction with physical functioning.

B. Mental health/Psychological

Body image, positive and negative feelings, self-esteem, personal beliefs, spirituality, religion, thinking, learning, memory and concentration. Items 5,6,7,11,18 and 26 of the questionnaire represent psychological dimensions.

C. Social Relationships

Personal relationships, received social support, sexual activity. Items 19, 20 and 21 of the questionnaire represent social dimensions.

D. Environment

Freedom, safety, environment, physical environment, transport, finances, information, accessibility of health and social care, leisure time. Items 8,9,13,14,22,23 and 24 of the questionnaire reflect satisfaction with one's environment.

Each question was assigned an appropriate number of points from 1 to 5, and the patient had to choose from the following possible answers: 1 point-very dissatisfied, 2 points-dissatisfied, 3 points-neither satisfied nor dissatisfied, 4 points-satisfied, 5 points-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 WHO-QOL-BREF questionnaire. The scale also included items (Questions) that were analysed separately: Question 1: pertaining to the individual overall perception of quality of life; Question 2: pertaining to the individual overall perception of own health.

STATISTICAL ANALYSIS

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

RESULTS

This study assessed the quality of life of parents of children with cerebral palsy. Thirty caregivers with children with cerebral palsy were enrolled in the study. The mean age of the parents viz. father was 29.93 years \pm 4.32 (SD) and mother was 25.50 years \pm 3.35 (SD). Mothers were the principal caretakers in all 30 children and majority (63.3%) were homemakers.

Most of the subjects were from nuclear families and 93.3% of children belonged to families of lower socioeconomic class. The mean age of children with CP was 4.23 years (SD-2.23) and majority of children had one or more co-morbidities. Intellectual disability (90%) and epilepsy (70%) were the commonest co-morbidities observed (Table-1). On functional status assessment as per GMFCS grading, 14 children (46.66 %) had level III impairment, 13 (43.33%) had level IV impairment and 3 children (10%) had level V impairment. The mean scores of 4 domains of quality of life of caregivers were as per Table No-2.

The main affected domain was social functioning with lowest mean score followed by psychological and environmental functioning and the least affected domain was physical functioning. The overall quality of life and satisfaction with their own health was also assessed and scored. Seventy percent of parents reported their overall quality of life as neither poor nor good and more than half of the parents were satisfied with their own health status. (Table No-3). It was observed that parents who had children with more severe disease as per the type of CP and impaired functional status as per GMFCS grading were found to have lower mean scores in social, psychological, and environmental domains (Table No - 4 & 5).

Parameters		No. of Cases	%
Age of the Child (yrs.)	2-5	20	66.66
	5.1-8	7	23.33
	8.1-12	3	10.00
	Mean±SD	4.23±2.33	
Gender of the Child	Male	18	60
	Female	12	40
Term/ Preterm	Full Term	17	56.67
	Preterm	13	43.33
Birth weight (Kgs)	<1.5	5	16.67
	1.5 - 2.5	20	66.67
	>2.5	5	16.67
Type of Cerebral Palsy	Spastic Diplegia	14	46.66
	Spastic Quadriplegia	12	40.00
	Dystonic Type	4	13.33
Co-morbidities	Intellectual Disability	27	90
	Epilepsy	21	70
	Feeding Difficulty	17	56.6
	Hearing and Speech Impairment	15	50
	Behaviour Problems	15	50
	Vision Impairment	8	26.67

Table 1. Sociodemographic Profile of Children with CP

Parameters	Domain Score	
	Mean	SD
Physical	24.50	2.97
Psychological	18.23	1.50
Social	9.33	1.49
Environment	20.87	2.45

Table 2. Descriptive Statistics of Quality of Life of 4 Domains

QOL score	Percentage of parents
Very Poor (1)	0%
Poor (2)	13.33%
Neither Poor nor Good (3)	70%
Good (4)	16.67%
Very Good (5)	0%
Total	100%
Health Satisfaction	Percentage
Very Dissatisfied (1)	0%
Dissatisfied (2)	6.67%
Neither Satisfied Nor Dissatisfied (3)	26.67%
Satisfied (4)	66.67%
Very Satisfied (5)	0%
Total	100%

Table 3. Individual's Overall Perception of Parents' Quality of Life and Health Status

Parameter	Type of Cerebral Palsy			GMFCS Grading		
	Diplegic (n=14)	Quadriplegic (n=12)	Dystonic (n=4)	Level 3 (n=14)	Level 4 (n=13)	Level 5 (n=3)
	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD	Mean±SD
Physical	20.21±1.762	22.00±2.449	19.75±3.686	20.79±2.190	21.46±2.436	18.67±3.215
Psychological	17.64±1.499	18.58±1.311	19.25±1.5	17.64±1.499	18.85±1.345	18.33±1.528
Social	9.07±.917	9.17±1.337	10.75±2.872	9.00±1.359	9.85±1.573	8.67±1.528
Environment	24.50±2.902	24.25±3.166	25.25±3.304	24.86±1.994	24.38±3.841	23.33±3.215

Table 4. Correlation between Type of Cerebral Palsy and Functional Status with QOL

DISCUSSION

The presence of a disabled child in a family usually disrupts family functioning.

The reactions of parents once the disability diagnosis is disclosed, puts them in phases of confusion, despair, anger, denial and frustration and finally acceptance.

The research on quality of life (QoL) of CP and their parents is scarce in India. This study explored the QOL among parents of children with cerebral palsy in the areas of physical, psychological, environmental and social domains. Overall quality of life and the general health status were also assessed. Majority of caregivers with affected children were from lower socioeconomic class living in nuclear families and lacked the support of family and relatives. They had to face numerous challenges and difficulties in taking care and upbringing of a child with cerebral palsy. Most of the mothers of children with severe disability could not participate in family gatherings or attend any social functions. Interpersonal relations and care of other siblings was sometimes affected at the cost of care of the disabled child. The major affected domain in this study was social functioning with a mean score of 9.33 ± 1.49 (SD).

Most of the mothers reported experience of negative feelings, anxiety regarding the health care needs of the child, education, self-dependence and unpredictability of future of child. Some of them described a feeling of loneliness in the fight against care of the child's needs who had disability and sought solace by visiting spiritual places and religious advisors. They lacked the support of relatives, friends and peers. Few mothers had low self-esteem and spent sleepless nights. In the study by Okarouska et al⁽¹³⁾ they reported that parents had a feeling of unfulfilled obligations, guilt because of disability, fatigue due to many hours of caring of child, lack of rest, which often lead to emergence of conflicts and crises in family. Similar observations were also reported by Deepti et al⁽¹⁴⁾ and Nimbalkar et al⁽¹⁵⁾ In a study by Shradha Diwan et al⁽¹⁶⁾ they found that 70% of mothers were suffering from mild-moderate level of depression and had affected QOL.

Lack of awareness about availability of appropriate health care facilities in the accessible vicinity, lack of easy availability of transport services to reach the facility, scarcity of intervention and rehabilitative services hindered the quality of care of affected children and in turn increased the parental stress. The mean score of environment domain was 20.87 ± 2.45 . Most of the caretaker's time was dedicated for the care of children with CP to fulfil their basic needs and they did not have enough time for leisure for themselves. A part of the family budget was exclusively spent on the medications to be administered to the affected child and hospital visits. Presence of one or more co-morbidities, insufficient finances and limited resources increased the burden on family expenditure and thus care of the affected child. For the organization of family life in which there is a child with cerebral palsy, the most important are the child's functional capabilities, which are mostly dependent upon the degree of disability. Limitations in the child's independence are a greater burden on the parents.^(13,17)

The quality of life of parents in this study was more affected in children with functional disability status of GMFCS score III and above. It was also observed that parents were unaware of the facilities and concessions provided by the state for such disabled children.

The findings were consistent with the study by Deepthi et al⁽¹⁴⁾ and Mohammed et al⁽¹⁸⁾ the mean age of mothers of affected children was 25.5 ± 3.35 years that represented early adulthood and majority were homemakers and this helped them cope with the child's demands and they could perform the daily household activities. Smaller family size and favourable home environment with all amenities like water and sanitation helped them to maintain a better physical health and they faced less fatigue. The mean score for physical domain was 24.5 ± 2.97 which was the least affected. The overall quality of life was described as neither good nor poor by 70% of parents, 16 % reported the quality of life as good and 13.33% reported as poor. More than half of parents (66.67%) were satisfied with their own health. In the study by Okarouska et al⁽¹⁸⁾ more than half of the parents described their QOL as good and were satisfied with their own health. This may be due to the fact that parents would have surpassed the phase of frustration, anger and denial and accepted that they had to cater to the needs of child with cerebral palsy with disabilities and co-morbidities. The study data depended entirely on the parents' subjective assessment of their own QOL that influenced the results of the study.

Although the diagnosis of cerebral palsy can have devastating effects on a family as a whole, the quality of life of the family members can be high if the proper support and perspective, coping strategies, and individualized family care are present. The service providers should aim at establishing a family centered programme and interventions should be addressed to the family as a whole to meet the health care needs of children with cerebral palsy and to assist parents in taking care of their affected child and psychological and social support to the mother.

CONCLUSION

Most of the parents reported the overall quality of life as neither good nor bad may be because they would have learned to cope with the situation. The major affected domain was social followed by psychological domain. Majority of parents were satisfied with their own health. Most of the difficulties were due to lower socioeconomic class, limited finances, lack of awareness about the disease and the available health care facilities.

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