

Assessment of Quality of Life in Parents of Children with Cerebral Palsy

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Abstract

Background: Cerebral palsy is a term used to describe a broad spectrum of motor disability which is non progressive and is caused by damage to the brain at or around birth. Care of a child with cerebral palsy is a source of tension and struggle for parents and causes many problems in meeting the child's needs. Understanding the quality of life of this category of parents, will contribute entire and sufficient physiotherapeutic interventions by various techniques and examine what structural changes could be made to increase parent satisfaction.

Study Design: This study is a cross sectional study approach to assess the quality of life of these parents in Pune. A sample of 30 parents of children of cerebral palsy age 3-17 years was selected through convenient sampling. Data were collected using WHO-QOL BREF, Parental stress index, Beck depression inventory questionnaire, focusing on quality of life, stress and depression of parents.

Method: 30 Participants were selected based on the inclusion and exclusion criteria. Convenient sampling was done. Informed consent was obtained before data collection. Demographic details were recorded, and participants responded to the questionnaire, focusing on physical health, psychological health, social relationship and environmental barriers, stress and depression level. Descriptive statistics analyses were conducted to analyze the data.

Results: The result showed as compare to father mother experienced lower quality of life, average depression level and increased stress level. This finding emphasizes the quality of life is severely affected suggesting the need to have family- centered approach for the management of children with cerebral palsy and evaluate unique challenges and experiences of parents to improve communication and support.

Conclusion: This study concludes that the Quality of Life in Mothers is lower than that of Fathers of Cerebral Palsy child.

Keywords: Cerebral palsy, Quality of life, Parents of Cerebral Palsy child

Introduction

Cerebral palsy is a term used to describe a broad spectrum of motor disability which is non progressive and is caused by damage to the brain at or around birth. Although the damage is non progressive, the clinical picture changes as the nervous system develops and the child grows ^[7]. It is also known as Little's disease as term was first described by William John Little in the year 1834 in which he mentioned that spasticity occurs due to damage to the brain during infancy, preterm birth, or birth asphyxia ^[11]. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation,

perception, cognition, communication and behavior; by epilepsy and by secondary musculoskeletal problems ^[5] .

Care of a child with cerebral palsy is a source of tension and struggle for parents and causes many problems in meeting the child's needs ^[1]. A child with cerebral palsy and specialized care, which exceeds that of a normal child and therefore requires more attention by parents .All of these contribute, causing the family to suffer physically and psychologically ^[4]. Caring for a child with cerebral palsy exposes the parents to challenges, some of which are related to the nature of the child's disease, and some are due to a shortage of facilities and lack of attention to the parents' needs. Therefore, to promote the parents' health and provide better care services to the afflicted child, it is important to recognize the parents' problems and remove such obstacles ^[1].

Because of the functional limitations experienced, some children with CP are dependent on others for assistance with daily activities, which leads to long-term caregiving that far exceeds the usual needs of typically developing children ^[2]. Providing the high level of care required by a child with long-term functional limitations can become burdensome, and may affect both the physical and psychological health of the caregiver. Caregiving is an expected aspect of being a parent of a small kid, but it takes on a whole new meaning when a child has functional limitations and requires long term assistance ^[8].

This role takes on an entirely different significance when a child experiences functional limitations and possible long term dependence. The main challenges for parents of children with chronic illness are problems and effectively carry on with daily requirements of everyday living. Consequently, the task of caring for a child with complex disabilities at home might be somewhat daunting for caregivers. The provision of such care may prove detrimental to both the physical health and the psychological well being of parents of children with chronic disabilities, with limited social support, there are likely to be more severe in resource poor environment ^[9]. Caring for a child with a disability affects the role of both parents, because they are usually the primary caregivers for the child. Mothers who care for their children experience many challenges also they lack employment opportunities as well as marital problems ^[2] .Within the field of the quality of life, the world health organization (WHO) includes -: Physical health, mental state, Independence, Social relations, Environment, Religion beliefs, Determination, conflicting views ^[4].

The Quality of life about parents with children diagnosed with cerebral palsy may vary with general population of parents with normal children^[4] .Changes in healthcare system and social attitude have resulted in most children staying at home in the care of family rather than institution .In order to develop a family- centred care practice , it is imperative to understand and address the psychological problems experienced by caregivers of affected children .In a country like India there are significant differences between the environments of urban and rural areas which is responsible for the lack in the awareness about the condition. ^[12]

Materials and Methods

Study design

The survey study was conducted as cross sectional study. Data was collected by using WHO-QOL BREF, Parental stress index, Beck depression inventory questionnaire, focusing on quality of life, stress and depression of parents. Participation in the study was voluntary and anonymous. This study has been performed in accordance with ethical standards.

Participants

30 Participants were selected based on the inclusion and exclusion criteria. Convenient sampling was done. Informed consent was obtained before data collection. Demographic details were recorded, and participants responded to the questionnaire, focusing on physical health, psychological health, social relationship and environmental barriers, stress and depression level.

Ethics, consent and participation

Participants in this study received a consent form which introduced the research project by including title of the study, aims and reassuring the participants their responses and information confidentiality. Consent was given to each parent.

Data collection

A sample of 30 participants of cerebral palsy child recruited from Pune, age of child 3 to 17, was selected according to inclusion and exclusion criteria.

Questionnaire

WHO-QOL BREF, Parental stress index, Beck depression inventory questionnaire was used to assess the quality of life of parents.

Statistical analysis

Two-tailed test was used for null hypothesis testing and statistical significance. SPSS and Advanced excel was used to analyze the Quality of Life in Parents of Cerebral Palsy.

Results

30 Parents were participated in the study. Mothers of age group 30-35 and fathers of age group 35-40 are more dealing with cerebral palsy child and are mostly targeted. Cerebral palsy child of age group 4-8 were more than 10-16 in which 12 were female and 18 were male child. The results concluded that Quality of Life of Mother is more affected as compare to Father.

Demographic Data-

Parents of Cerebral Palsy child-

Table no .1 shows Age group of mothers participated in research

Age Groups	Mother
25-30	11
30-35	14
35-40	5
40-45	0

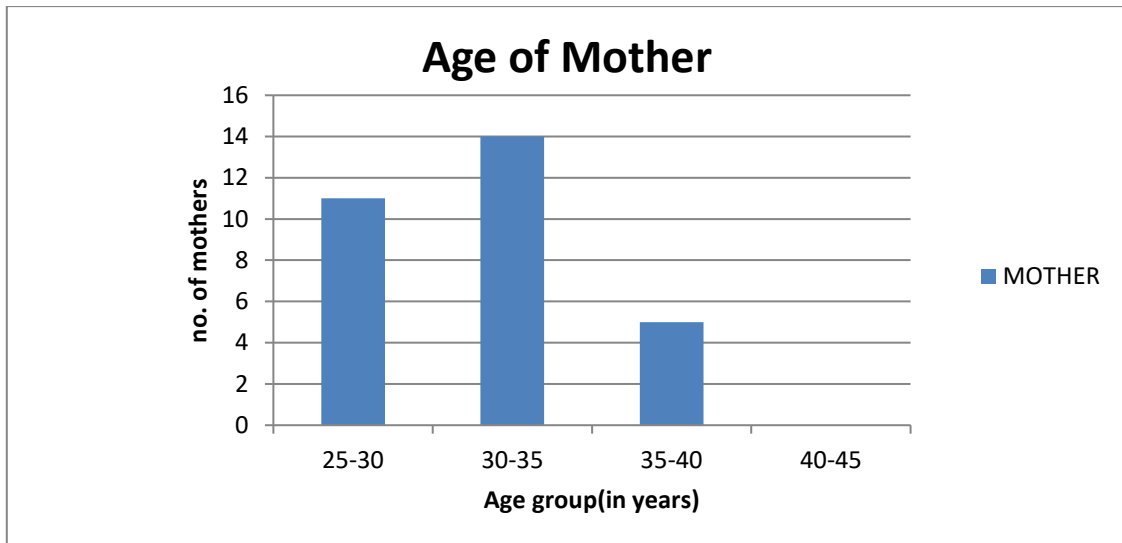


Table no.2 shows Age group of Fathers participated in research

Age Groups	Father
25-30	1
30-35	8
35-40	17
40-45	4

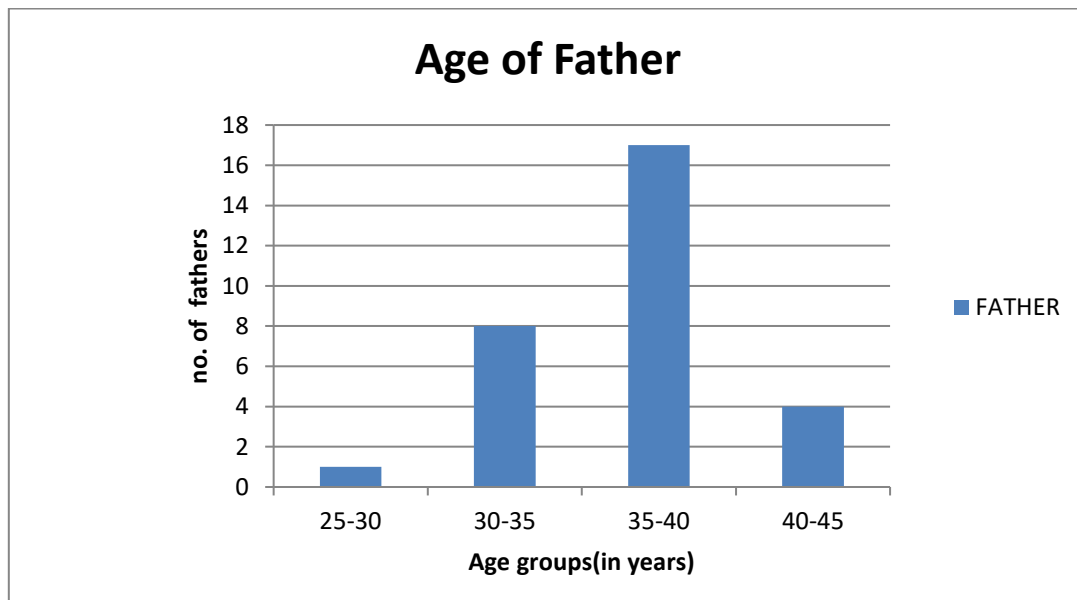
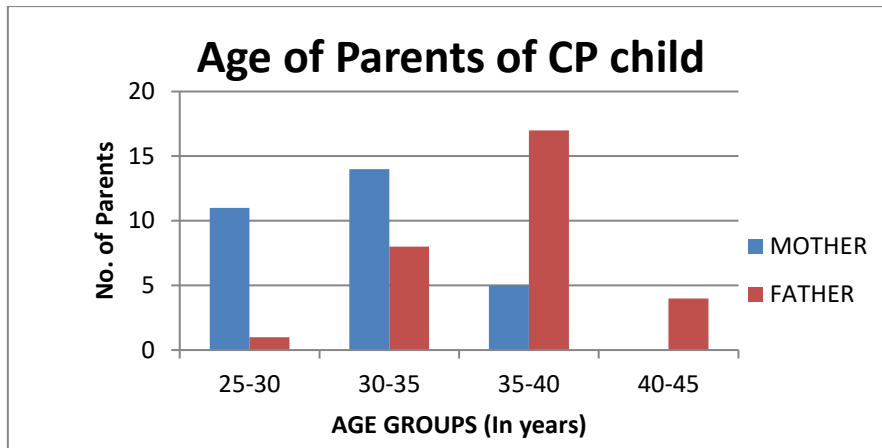


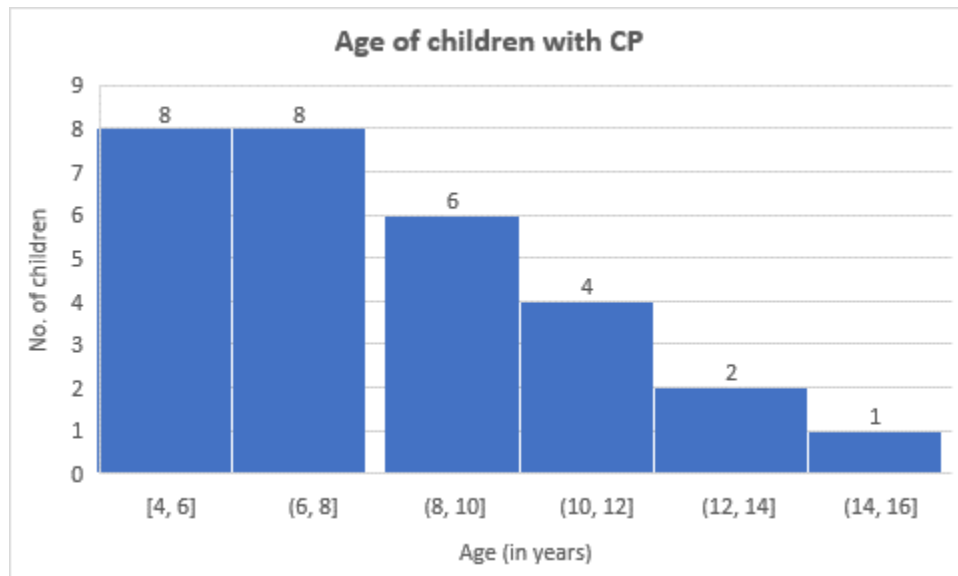
Table no.3 shows Comparison of Age group of Parents of Children with Cerebral Palsy

Age Groups	Mother	Father
25-30	11	1
30-35	14	8
35-40	5	17
40-45	0	4

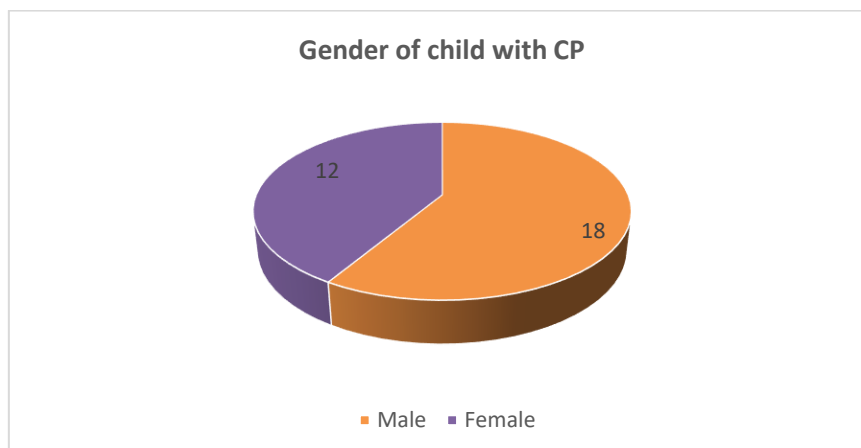


Cerebral Palsy child -

1. Graph shows the Age of children with cerebral palsy divided into age groups.



2. Pie chart shows the interpretation of female and male children with cerebral palsy



	Mother	Father	Mean	Standard deviation
Beck Depression Inventory	30	30	16.8	7.44
Parental Stress Index	30	30	82.45	11.55
WHO QOL-BREF	30	30	96.21	9.2

Discussion

The primary objective of this study is to investigate the Quality Of Life of Parents of Cerebral Palsy. To contribute physiotherapy in improving the quality of life of parents with various physiotherapeutic techniques and increase their child functionality and gain independence in society. In terms of Quality of Life, questions were asked to the parents who include their physical life, psychological health, social relationship and environmental barriers and few questions were about level of stress and depression they are experiencing. Scales used were WHO-QOL BREF which uses to assess physical health, psychological health, social relationship, environmental issues and the mean score of each domain is used to calculate the mean score, it will make it possible to carry out multiple views of quality of life. Parental stress scale help to assess positive and negative impacts on parents .A 5 point scale-strongly disagree ,disagree ,undecided ,agree, strongly agree .The outcomes is to improve parents parenting capacity. Another test is Beck depression scale which helps to assess the severity of depression .Level of depression helps to find out highest and the lowest scoring which concludes the severity in parents.

In this study three scales were administered for the assessment 30 parents participated with their child's age group (3-17years) both male and female. The aims and objectives were explained to both mother and father; each parent filled the consent form before performing the study. The sample was collected as per inclusion criteria. Both the genders were participated in study .In WHO-QOL BREF scale outcome was observed as there was significant difference observed in quality of life of mother and father of child with cerebral palsy .Thus , when we compare the scores of mother and father in the sample, the average quality of life in fathers is higher than that of mothers ,which was due to family members and friends failed to accept the children with cerebral palsy .The negative attitudes experienced were partly as a result of traditional and cultural beliefs and partners who, with, or without their families blaming the mothers for the condition of their children.

In Parental stress scale outcome was observed as there may be difference in stress levels of mother and father of a child with cerebral palsy when we conclude the result we find stress levels may affect the quality of life, as caring for child with cerebral palsy exposes the parents to challenges like psycho-emotional and social challenges this is all linked to behavioural problems of child.

In Beck depression scale the outcome was observed as there was significant difference observed in mother and father depression levels. Thus when we compare the scores of mother and father in the sample, the average depression is higher in mothers than that of fathers, which was due to marital relationship amongst families of children with cerebral palsy and managing the chronic health problems of a child to deal with the demands of everyday life. Child's motor, intellectual, emotional and behavioural problems along with presence of pain and sensory impairment led to increase in the burden for the family members.

Limitations

Cerebral palsy condition have much smaller population that impact on Parents Quality of Life which is

often influenced by various factors like financial burden ,social support and health care facilities . Level of social networks, community resources and support systems may not be fully measured. The long term effects of care giving stress on parents may not be fully assessed in short term assessments. The availability and effectiveness of social support creates an impact on parent's quality of life. Parents facing financial burden may not evaluate economical status of the family.

Conclusion

According to the result of the study it confirms that physical health, psychological, emotional, and social relationship adversely affect Parents Quality of Life. The study reveals that there is lack of support and understanding of the condition from family and friends which leads to psychological problems such as isolation, worries and stress. It is therefore recommended that programmes and policies need to be implemented to support the mothers and inform society about various aspects of disability, especially in children. A family-centered approach for the management of children with cerebral palsy should be taken, as this helps for recovery and make awareness about the condition and importance of rehabilitation for the child.

Future scope

More specialized assessment tools can be designed to evaluate unique challenges and experiences of parents, capture both short term and long term effects of care giving on various aspects of their life, online platforms and mobile apps can be easier and frequent assessment of parents QOL can be measured.

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