ORIGINAL RESEARCH PAPER
Volume - 10 | Issue - 01 | January - 2021 | PRINT ISSN No. 2277 - 8179 | DOI : 10.36106/ijsr
INTERNATIONAL JOURNAL OF SCIENTIFIC RESEARCH

QUALITY OF LIFE AMONG THE FATHER AND MOTHER OF CHILDREN WITH CEREBRAL PALSY

Medicine

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ABSTRACT

BACKGROUND: "Quality of life (QoL) has been described as an individual's perception of his/ her own status in life as to cultural features and values systems". Cerebral palsy (CP) is the commonest physical disability in childhood. The disabled child's dependence on primary caregivers especially father and mother in their daily activities which may leads to higher level of stress on them. The caregivers of children with CP should be able to overcome the difficulties and complication arising from the child's impairment. QoL in families can be affected when a child has CP.

Aims and objectives: The objective of the study was to explore the QoL of fathers and mothers of children with CP.

METHODS AND MATERIALS: Using convenience sampling, subjects were been recruited. Screening was done using Gross motor functional classification system E&R children were classified into level III, IV and V. 50 fathers and mothers of same child who fulfill the inclusion criteria were asked to fill the WHO QoL–BREF scale individually. The scores were collected for statistical analysis.

RESULT: The collected data was analyzed using Wilcoxon signed rank test and found the mean difference of fathers and mothers score were 4.94 (p=0.010); 5.30 (p= 0.061); 4.94 (p=0.304); 3.48 (p=0.143) for Physical health, Psychological, Social relationships, and Environmental domains respectively. However, Physical health and Psychological domains mean differences were statistically significant ($p<0.05$) but Social relationship and Environment domains were not significant.

CONCLUSION: This study concludes that both mothers and fathers of children were been affected in their Quality of Life. The fathers have a higher mean QOL in all the domains when compared to mothers of children with CP; however fathers are also affected in all domains.

KEYWORDS

Cerebral Palsy, Quality of Life, Caregiver.

INTRODUCTION:

Quality of life(QoL) has been described as an individual perception[1]and multidimensional[2]of own his/ her status in life as to cultural features, value system[3] and it incorporates the individual physical health, psychological status, level of independence, social relationship, financial wellbeing, spiritual and their interaction with environment. It is considerable factors essential to be taken in account while individual health status is determined[4]. Cerebral palsy (CP) is the commonest physical disability in childhood[5] and living with a chronic condition[5] not only affects the child but remarkably influence life of their family[6,7] especially the primary caregiver, who often child's father and (or) mother[8]. Incidence of CP is 2.0 to 2.5 per 1000 lives birth in developed countries[5,9] in India prevalence of CP is in the range of 1.5 to 2.5 per 1000 live birth[10], most of children with disabilities lives in developing countries[11].children are of great concern to the family as well as society, parenting a child with CP is associated with increased burden and stress and poor health and wellbeing in the primary caregiver. The aim of the study therefore was to find out the QoL of the parents of children with CP, we focused on the objective of comparing the QoL of Fathers and Mothers.

METHODS:

Using convenience sampling method 50 Fathers and mothers, those who attended the Physical Medicine and Rehabilitation department, Christian Medical College and Hospital, Ludhiana during the study period between May to October 2016 and whose children were diagnosed as CP were screened using Gross motor functional classification system E&R (GMFCS E&R). The consent was taken from fathers and mothers, who fulfilled the inclusion criteria like age limitation of children between 5 to 18 years, and children who are classified as level III, IV and V according to GMFCS E&R. Single parent and parent's age more than 50 years and those children who were classified as level I and II according to GMFCS E&R were been excluded. Both father and mother filled the World Health Organization – Quality of Life BREF scale separately, assistance were given as per the need of the parents. The scores were taken for the statistical analysis using Wilcoxon Signed Rank test.

MATERIAL USED:

GMFCS E&R: The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. The focus of the GMFCS is on determining which level best represents the child's or youth's present abilities and limitations in gross motor function. It is a 5 – level clinical classification system that describes the gross motor function of the people with CP developed by Robert Palisano, Peter Rosenbaum. Its inter-rater reliability was high 0.994-0.996 and intra rater reliability was 0.972 – 0.996.

The World Health Organization Quality of Life – BREF: WHO QoL BREF is an abbreviated version of WHO QoL-100. It allows the assessment of individual facets relating QoL. It is available in 19 different languages. This consists of 26 questions with four domains i.e. Physical health, Psychology, Social relationship and Environment. It was drafted by Alison Harper and panel on behalf of WHO QoL group on December 1996 in WHO Geneva.

RESULT:

Table 1: Difference in mean QoL between fathers and mothers.

S.No	Domains of QoL BREF	Mothers Mean±S.D	Fathers Mean±S.D	p value
01	Physical health	36.24±13.30	41.18±15.08	0.010
02	Psychology	35±15.44	40.3±15.83	0.050
03	Social Relationship	41.4±25.93	46.36±25.79	0.304
04	Environment	30.64±15.17	34.12±15.78	0.143

S.D : Standard Deviation

The collected data was analyzed using SPSS 16 Wilcoxon Signed Rank test. In this study, we found the mean difference of mothers and fathers were 4.94 (p=0.010), 5.30 (p=0.05), 4.94 (p=0.304), 3.48 (p=0.143) in different domains like Physical health, Psychology, Social relationship and Environment respectively.

The fathers have a higher mean of QoL in all domains. However,

Wilcoxon Signed Rank test showed that difference of mean in physical health and Psychology domains are statistically significant but in Social Relationship and Environment domains were not significant at the $p<0.05$.

DISCUSSION:

CP is a most common developmental disability of early childhood[3,4,12] and persisting throughout the lifespan and there is no cure, thus children and their families live with the disability[13] on a permanent basis. A child with CP has multiple care needs that go beyond the ones of a child of the same age without the condition, consequently demanding a greater involvement from parents[14].

This present study found, a difference in mean between the QoL of fathers and mothers of children with CP. The result show that parents of children with CP affects in various aspects of QoL which supports a pervious study done by Elena M Marron, that physical or mental disabilities at birth or during growth and development force the family to confront stages of shock, denial and guilt that can eventually lead to stress and anxiety for the whole family[5] which in turn affects their QOL.

Raina P et al[12], concluded that one of the main challenges for parents is to manage their child's chronic health problem effectively and juggle their role with the everyday living[11], caring for the children with disability requires more time from caretakers which have impacts on their social relationship domain of QoL. Guilliamon et al[13], in QoL and mental health among parents of children with CP stated that the mothers of children with CP have lower level of QoL and greater depression mood than the mothers of typical children. In Iran by Ahvaz with 21 mothers of children with CP and 21 mothers of normal children assessed QoL and found that there was significant difference in all domains of QoL with mean and p value of mothers of healthy children 74.96 ± 6.62 and mothers of children with CP 47.13 ± 11.11 ($p= 0.0001$)[7]

Rearing a child with impairment often causes detrimental effect on requirement caregivers health. These disable children may have some limitation that requires a long term care[14] which exceed the usual need of normal children[15]. These children need special care, frequent medical checkup and rehabilitation and they fail to take over their role in society which affects their social relationship and health related QoL [3]. Meisa P[16] stated that treatment and caring of children with CP is burdensome to parents in terms of cost, time and stress, leading to the risk of unstable family conditions and low ability to cope with problems.

Parents of children with CP often experience higher levels of stress than other parents. The cerebral palsy children are highly dependent on mothers for their day to day activities due to which the mothers experience psychological distress. This excessive responsibility may adversely affect the physical and the psychological health of caregivers[17].

Brehout et al,[18] stated that care of children with disability require more attention and longer duration of care compared to the care of normal children. It results in burden on parents and family. Excessive responsibility can adversely affect their physical, psychological and social health. Sajedi F et al[19] found mothers of children with different level of disability tolerate higher level of stress. Children with chronic medical conditions causes emotional and behavior problems in the mothers. She also added that mothers having CP children have depressive symptoms and lower QoL. Latefa Ali[20] in his study found that the QoL of parents of children with Autistic disorder affected by their stress levels and social economic status.

The present result is also supported by other previous studies which conclude that the Psychological, Physical health and Social relationship of caregivers, who were primarily mothers were strongly influenced negatively by their child behavior and caregiver demands[4-6,9,18-20].

CONCLUSION:

Fathers and mothers are affected in all domains of QoL. In our study, even though fathers have higher mean value than that of the mothers, fathers are found to be scored less than fifty percent in all domains, which indicate that, fathers QoL is also affected. So, better understanding of the way in which the child's condition affects the parents QoL, enhances the treatment of the entire family, through greater focus on rehabilitation for these children and the caregivers.

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