

# A Study to Find the Quality of Life of Parents of Children with Neuromotor Disorders

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**ABSTRACT:** This study compared the quality of life (QOL) of parents of children with neuromotor disorders to that of parents of healthy children. A total of 248 participants were divided into two groups: Group A comprised 124 parents of children with neuromotor disorders, while Group B comprised 124 parents of healthy children. Physical paperwork, like as consent forms and the WHOQOL-BREF questionnaire, were filled out by participants. . A comprehensive descriptive statistical analysis was used to compare the QOL between the two groups. The study achieved a 100% response rate. Results indicated significant differences in QOL between parents of children with neuromotor disorders and those of healthy children across the physical, psychological, social, and environmental domains. Surprisingly, the QOL of parents of healthy children was also impacted, particularly in the physical and environmental domains. These findings highlight the challenges faced by both groups of parents. The study suggests that interventions aimed at improving QOL should consider the unique needs of parents of children with neuromotor disorders as well as those of parents of healthy children, especially in the physical and environmental aspects. Further research could explore specific interventions to support these parents and enhance their QOL.

**KEYWORDS:** Quality of life, Neuromotor Disorders, WHOQOL-BREF, Parent.

## I. INTRODUCTION

"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 goals, expectations, standards, and concerns" is how the World Health Organization defines quality of life. Wealth, employment, the environment, mental and physical health, education, leisure and recreation, social belonging, religious views, safety, security, and freedom are all considered standard indices of quality of life.<sup>[16]</sup> There are many different contexts for quality of

life, such as international development, healthcare, politics, and work. The support that parents receive from their co-parenting partners, communities, and employers is favorably correlated with their quality of life.<sup>[3]</sup> A parent's sense of well-being and mental health are closely linked to their quality of life.

The majority of parents experience great joy upon the birth of a child, but they also acquire additional responsibilities and duties on top of their already existing ones. A process of adjustment is frequently required, and gradually the family forms new routines and habits that include taking care of this new member.<sup>[16]</sup> But, the role of caregiver for parents changes significantly if physical or intellectual problems are identified in the early years of the child's life. Evidence indicates that although many parents manage the additional responsibilities of raising a child with a disability rather well, taking care of a child with a chronic illness can become demanding and have an influence on the physical and mental health of the parent.<sup>[11]</sup>

A neuromotor disorder is an acquired or developmental illness that usually impairs fine motor skills, posture, gross motor capacity, and mobility. Damage to the central nervous system is the root cause of neuromotor diseases. This may be the result of developmental issues or damage to the growing circuits in the brainstem, spinal cord, thalamus, cortex, or cerebellum. Children may exhibit a variety of issues at once, such as sensory impairment, cognitive challenges, contracture, weakness, issues with muscle tone, and other medical concerns. There is a lot of variation within the various diseases as well as a lot of variation in the presenting features of those who have been diagnosed.<sup>[14]</sup>

Cerebral palsy (CP), along with muscular dystrophy and spina bifida, is one of the most prevalent neurological disorders. A few other neurological conditions that can lead to disability include autism, attention deficit hyperactivity disorder (ADHD), spinal muscular atrophy (SMA), amyotrophic lateral sclerosis (ALS), and

intellectual disability (also known as mental retardation).<sup>[8]</sup>

Prevalence of these disorders: India is a major developing country with inadequate resources that serves approximately 18% of the global population. Neurological disorders, both fatal and non-fatal, contribute significantly to India's non communicable and communicable disease burden.<sup>[9]</sup> A systematic and complete data study of a neurological condition among the Indian population is necessary in order to provide insight into disease prevalence and the factors associated with it. Such data will assist policy in a cause to plan funds: firstly, for the employment of the trained workforce in the field of neurosciences; secondly, for the establishment of infrastructure; and thirdly, to meet healthcare needs (based on social, cultural, and ethnic variations) of communities, regions, and nationally among individuals suffering from a variety of neurological disorders.<sup>[4]</sup>

Physiotherapy Interventions for Children with Neuromotor Disorders: In the Netherlands, Neuromotor Task Training (NTT) has recently been developed specifically for children with DCD, as the existing intervention programs have no or little effect and are not explicitly designed for these children. . NTT takes a cognitive neuroscience approach to motor control, which means that several cognitive and motor control processes can be distinguished during the preparation and execution of functional motor tasks, such as motor-task information processing, action planning, and initiation. The standard assessment of NTT comprises an evaluation of the child's deficits in a specific functional motor task. During intervention, therapists use functional exercises to target the specific motor control mechanisms thought to be implicated. NTT is a task-oriented strategy that focuses on teaching children the skills they need in daily living. The greater the similarity between skills and the situations performed during therapy and skills required in daily life, the greater the likelihood of skill transfer.<sup>[14]</sup>

## II. MATERIALS AND METHODOLOGY

This is a comparison based study. The WHOQOL-BREF questionnaire was distributed to the parents of children with neuromotor disorders and parents of normal healthy children in Pune.

A total 248 parents were approached via convenient sampling method. 124 participants were parents of children with neuromotor disorders and

other 124 participants were parents of normal healthy children. Participants were required to meet specific inclusion and exclusion criteria to ensure the validity of the results. Physical forms containing consent form and questionnaire were distributed by visiting clinics, hospital and homes.

Before commencing the study, the participants were fully informed about the confidentiality of their personal information and they were assured that their participation in the study was entirely voluntary.

The WHOQOL-BREF is an abbreviated 26-item version of the WHOQOL-100. The WHOQOL-BREF contains one item from each of the 24 facets of QOL included in the WHOQOL-100, plus two 'benchmark' items from the general facet on overall QOL and general health which is not included in the scoring. The questionnaire aims to gather information about the quality of life of individuals in four main domains. The responses from each question were scored by using 5-point Likert scale. The physical domain has seven facets/questions about pain and discomfort, energy and fatigue, sleep and rest, dependence on medication, mobility, activities of daily living, and working capacity. The psychological domain contains questions about positive feelings, negative feelings, self-esteem, thinking and concentration, body image, and spirituality. The social domain consists questions about personal relationships, sex life and practical social support. The environmental domain includes questions about financial resources, availability of information, recreation and leisure, home environment, access to health and social care, physical safety and security, physical environment, and transport.

The raw score was calculated for each domain and it was converted into a 0-100 score. The mean score was calculated for each group in all four domains and the comparison was made between groups by doing unpaired t-test. Descriptive statistics using mean, SD, t-value and p-value were utilized to compare QOL between both the groups. Graphs were included when possible. Demographic information such as gender, educational status, marital status and age of child was summarized. SPSS Version 23 and Excel was used for statistical analysis to compare the quality of life between parents of children with neuromotor disorders and parents of normal healthy children.

## III. RESULT

The research conducted aimed to compare the quality of life of parents of children with

neuromotor disorders and parents of normal healthy children. A total 248 parents participated, with demographics indicating predominantly females (62.5%), married (99.1%), went till secondary school (70.1%) and their child's age being 10 (19.3%). Graphs depicting gender, marital status, educational status and child's age provided a comprehensive overview of participant's characteristics.

The findings revealed that there is a significant difference in Physical Domain scores between parents of children with neuromotor disorders (45.22) and parents of normal children (61.29), indicating that the former group had lower physical well-being than the latter. This discrepancy could be attributed to factors such as healthcare access, physiotherapy services, physical activity, family support, and environmental factors. Low scores among parents of children with neuromotor disorders may be due to high caregiving obligations, a lack of support, or sleep difficulties. Addressing these discrepancies and providing fair access to healthcare and services is critical. More study is needed to identify specific causes and create focused solutions for this demographic.

Parents of children with neuromotor disorders and parents of children who are normal score significantly differently in the Psychological Domain; parents of normal children score higher (70.60) than parents of children with neuromotor disorders (51.21). Lower scores among parents of children with neuromotor disorders could be related to emotional stress from caregiving, social isolation from substantial care needs, or a lack of support. Parental guilt or self-blame may also contribute. Higher ratings among parents of normal children could be attributed to improved access to mental health care, coping methods, or social supports. The findings emphasize the need to address mental health inequities and create interventions for this population.

The Social Domain ratings of parents of children with neuromotor problems and parents of children without such illnesses differ significantly, according to the study. Parents of children with neuromotor problems scored significantly lower (48.66) than parents of normal children (73.12), suggesting potential differences in social well-being. Access to community resources, social support networks, and treatments may have contributed to the disparity. Parents of children with neuromotor impairments may encounter social stigma, prejudice, and difficulty managing caring and employment responsibilities. Addressing these

discrepancies is critical for improving the social well-being of parents of children with neuromotor disorders.

According to the study, parents of children with neuromotor problems and parents of children in the normal range differ significantly in the Environmental Domain scores. Parents of normal children received significantly higher scores (52.77) than parents of children with neuromotor problems (39.87), indicating potential differences in environmental well-being. Housing arrangements, outdoor access, environmental adjustments, and supportive living settings may have all played a role in this disparity. Parents of children with neuromotor disorders may encounter environmental challenges or barriers to their well-being. Addressing these inequities and providing access to appropriate living situations is critical. More research is needed to identify the exact environmental factors that influence these variances.

#### IV. DISCUSSION

This study highlights the components about the domains affected in terms of quality of life of parents of children with neuromotor disorders and parents of normal healthy children.

The study underlines the importance of personalized therapies and social support networks for improving their physical well-being. It also demonstrates the devastating impact severe disabilities can have on parents' physical and psychological health, emphasizing the significance of healthcare providers' knowledge and assistance. Empowerment programs focused on coping skills, stress management, and positive thinking, as well as self-help support groups, are recommended to improve parental quality of life, which can have a good impact on parental care and, as a result, their children's health.<sup>[16]</sup>

The study's findings highlight the significant impact of psychological factors on the quality of life (QOL) of parents of children with developmental disabilities, particularly in the areas of mood, sadness, worry, and self-dissatisfaction. Both mothers and fathers in the research groups had considerably lower QOL in these domains. Parental sentiments of incompetence and loneliness were significantly associated with psychological well-being. The study also emphasizes the widespread anxiety parents have about their own and their children's futures, which leads to misery, shame, self-blame, and social humiliation. These characteristics highlight the critical need for

comprehensive psychological support and intervention measures for parents facing similar situations.<sup>[9]</sup>

The results of the study also show how much caregiving obligations affect parents of children with impairments, in terms of their overall quality of life (QOL) and social relationships. The demands of caring for a special needs kid frequently occupy parents' daily routines, leaving little time for social activities and relationships. This isolation can cause increased stress and anxiety, worsening their quality of life. The emotional toll of managing their child's condition, along with the difficult nature of caring, highlights the need for tailored support services and treatments to ease these burdens and improve the quality of life of these parents.<sup>[3]</sup>

Financial constraints that limit access to treatment and rehabilitation choices not only cause stress, but also evoke feelings of shame and unmet responsibilities. This, combined with the physical and emotional demands of parenting, such as sleep deprivation and family conflicts, can have a negative impact on parental well-being. The lack of access to healthcare and support services, as well as constraints in transportation and leisure activities, exacerbate these issues, highlighting the importance of complete support systems for these families.<sup>[10]</sup>

## V. CONCLUSION

This study concludes by highlighting the significant disparities in parent's quality of life (QOL) between those whose children have neuromotor problems and those whose children are healthy. The results show that QOL scores are poorer for parents of children with neuromotor problems, especially in the physical, psychological, social, and environmental domains. Physical domain score of parents of normal children (61.29) suggests that there may be some challenges or limitations in physical health of parents of normal children such as chronic health condition, poor sleep, lack of exercises, work life balance and unable to perform self-care or leisure activities. Also the environmental domain score of parents of normal children (52.77) indicates that they might be facing challenges in financial resources, physical safety and security, health and social care, home environment and physical environment.

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