

Research Article

A Study of Quality of Life of Mothers Having Children with Special Needs

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A B S T R A C T

Introduction: Even though there is more and more written about the quality of life of mothers and families with disabled children, most of such studies have been done in Western countries. In India, little has been studied about the quality of life of mothers of disabled children. This study is aimed to understand the quality of life of mothers who have children with intellectual disability (ID) or locomotor disability (LD). Families caring for disabled children encounter unique obstacles and responsibilities compared to those caring for children without disabilities.

Method: In this scientific study, 300 mothers (100 mothers having children with intellectual disability, 100 mothers having children with locomotor disability, and 100 mothers having normal children) were selected from northern India. The WHO Quality of Life Brief Tool was administered to assess the quality of life in variables; the scale has four domains with 26 items.

Results: The result of the study showed that the F value for quality of life in mothers of intellectually disabled children, children with locomotor disabilities and normal children, the F value for quality of life was 203.774 which was significant at 0.001 levels of significance.

Conclusion: This shows that there is a significant difference in the level of quality of life among the group of mothers of normal children and children with intellectual and locomotor disabilities.

Keywords: Disability, Quality of Life, Mother of Children with Disabilities, Intellectual Disability, Locomotor Disability

Introduction

Taking care of a child with disabilities is challenging and can affect the family's financial, social, physiological, and psychological well-being.¹⁻⁵ Disability shows a significant impact on quality of life (QOL) not only because it lasts for adversity, but also due to prejudices and social attitudes

that still surround it and the effects it has on the emotional, social, and behavioural domains.⁶ Caregiving and its associated strain are seen as crucial factors in affecting the quality of life of mothers. Quality of Life (QoL) is widely recognised as an essential outcome measurement for chronic illness patients and their carers.^{7,8} Compared to

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parents of children who were healthy, parents of children with intellectual disabilities or autism spectrum disorders reported problems in all four areas of quality of life, namely physical health, psychological health, social relationships domain, and environmental domain.⁸

Families assume that the mother is primarily responsible for taking care of a child with a disability.⁹ A mother who takes care of her children often has health problems, such as loss of appetite, unusual eating, headaches, backaches, lower back pain, extreme fatigue, sleep problems, trouble concentrating, and stomach pain, because she doesn't have enough time to take care of herself.¹⁰⁻¹⁴ This is particularly the case for mothers, who are the main caregivers for their children. Another reason the mother is more stressed and unhappy than the rest of the family is that she is treated as though she caused the child's disability.^{15,16}

Recent studies have indicated that parental quality of life provides a more thorough evaluation of parental adaptation. QoL is a comprehensive and multifaceted concept that permits a comprehensive examination of positive and negative adaptation across multiple domains of functioning. It refers to the "view of an individual's place in life in the context of the culture and value systems in which they reside, and in connection to their objectives, expectations, and standards".^{17,18} The World Health Organization states that a person's QOL is how they feel about where they are in life, in terms of the objectives, expectations, principles, and concerns, as well as their culture and value system. It is a broad idea that includes a person's physical health, psychological or mental state, level of independence, social connections, personal beliefs, and how they relate to important things in their environment. The family of a disabled child changes many things to meet the needs of children. Having these kinds of children could cause a lot of physical and mental stress. Depending on the type of disability, caring for these children can be hard on the body and mind, which can affect the caregivers' QOL.¹⁹

According to the International Classification of Functioning and the World Health Organization, "children with disabilities" are those who have impairments, functional limitations, and participation restrictions or difficulties (ICF).²⁰ A disability is a physical or mental condition (impairment) that makes it more difficult for a person to undertake particular tasks (activities restrictions) or interact with the environment around them (participation restrictions).²¹ Disability occurs from the interplay of individuals with a medical and health condition, such as cerebral palsy, ID, Down syndrome and depression, with personal and environmental variables including unfavourable attitudes, inaccessible transportation and public buildings, and poor social support.²² There are many different forms of disability, including those that

affect vision, movement, communication, hearing, etc. The World Health Organization defines disability as having the following three dimensions:

1. **Impairments:** a change in the structure or function of a person's body or mind, for example, losing a limb, going blind, or having trouble remembering things
2. **Limitations in Activity:** such as difficulties in seeing, hearing, moving, or solving problems
3. **Participation Restrictions:** limitations on normal day-to-day activities like working, going out with friends and family, and getting health care and preventive services²³

The special needs of children frequently place a substantial demand on caregivers. Taking care of children with special needs has a negative impact on mothers' physical and mental health, as well as their social, cultural, and professional lives. This burden lowers the quality of life of caregivers by making it harder for them to sleep, get along with others, do everyday tasks, and stay strong.^{24,25} It has been noticed that children whose parents can adapt successfully to such adverse conditions experience a better quality of life than those whose parents are less adaptable.²⁶

Aim of the Study

The aim of the present study is to understand and compare the quality of life of mothers of children having intellectual or locomotor disabilities and those having children without disabilities.

Methodology

This study used a correlational study design and was conducted from December 2021 to August 2022. The sample for the study was collected using purposive sampling technique from NGOs, rehabilitation institutions, and special schools. A total of 300 mothers were selected for this study, among whom, 100 mothers had children with locomotor disability (LD), 100 had children with intellectual disability (ID), and 100 had normal developing children. A sociodemographic tool and the WHO QoL Brief (1998)¹⁷ scale were used for assessment. The sociodemographic tool was used for collecting the details about mothers e.g., name, age, socioeconomic status, marital status, educational level, residence (urban/ rural), and information about children's disability, i.e., type, name, age, and education. Quality of life consists of 26 items divided into four domains: 1) Physical health domain 2) Psychological domain 3) Social relationships domain, and 4) Environmental domain. Research data were collected from special education centres, NGOs, rehabilitation centres and institutions related to the field of disability in Uttar Pradesh and Delhi National Capital Region. All necessary permissions and consent were taken from the organisation and mothers before data collection, and they were explained the nature and purpose of this study. Data were analysed using M

(mean), SD (Standard Deviation), ANOVA, and post-hoc test; and all analyses were done using the SPSS software.

Inclusion Criteria

Educated mothers having children with mild and moderate intellectual disability or locomotor disability with the age range of children being between 6 and 18 years, and having the child's disability certificate were included in the study.

Exclusion Criteria

Mothers, who had any kind of psychiatric issues or disability, divorced mothers, and mothers having children with a severe and profound level of disability were excluded from the study.

Results and Discussion

Table 1 shows a comparison among mothers of children having intellectual disability, locomotor disability, and normal children on descriptive values, i.e., N (total sample size), mean, standard deviation, minimum and maximum score, for quality of life. It was seen that the mean score of mothers of intellectually disabled children was 73.89 and the standard deviation score was 12.345. The mean score of mothers of children having locomotor disability was 74.59 and the standard deviation score was 8.16, while the mean score of mothers of normal children was 98.06 and the standard deviation was 7.72.

This score showed that the mothers of normal children have a high quality of life as compared to the mothers of children with intellectual or locomotor disabilities. It also indicated that the mothers of normal children are high on

resilience as compared to the mothers of children with intellectual or locomotor disabilities. The findings also showed that the mothers of children having locomotor disability had a partially higher mean score than the mothers of intellectually disabled children.

Table 2 shows that the F value for comparison regarding quality of life was 203.774 which was significant at 0.001 level of significance. This shows that there was a difference between the quality of life of mothers of normal children and those with children having intellectual or locomotor disabilities.

Table 3 shows the values of the post-hoc test (multiple comparisons) of participants for quality of life. It was observed that the mean score of the difference between mothers of children with intellectual disability and those with locomotor disability was 0.70, which was not significant at any level of significance. The mean score of difference between mothers having intellectually disabled children and those having normal children was 24.17 which was significant at 0.001 level of significance. The mean score of difference between mothers of children with locomotor disability and those having normal children was 23.47 which was also significant at 0.001 level of significance. This result highlights that there are significant differences found between mothers of intellectually disabled children and mothers of normal children, and between mothers of children with locomotor disability and mothers of normal children in terms of QoL, but there was no significant difference between the QoL of mothers of children with intellectual disability and those having children with locomotor disability.

Table 1. Comparison of Quality of Life among Mothers having Children with Intellectual Disability, Locomotor Disability and Normal Children

Mothers of Disabled and Normal Children	N	Mean	SD	Min.	Max.
Mothers of children with intellectual disability	100	73.89	12.345	44	109
Mothers of children with locomotor disability	100	74.59	8.16	51	92
Mothers of normal children	100	98.06	7.72	77	113

Table 2. Comparison of Quality of Life in Mothers of Normal Children and Children having Intellectual or Locomotor Disability

Comparison Units	Quality of Life			
	Sum of Squares	df	Mean Squares Value	f Value
Between groups	37850.660	2	18925.330	203.774*
Within groups	27583.620	297	92.874	
Total	65434.280	299	-	

*Significant at 0.001 level

Table 3. Post-hoc Test on Quality of Life of Mothers of Normal Children and Children having Intellectual or Locomotor Disability

Area		Mean Difference	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Mother of ID children	Mother of LD children	0.70	1.36290	1.000	-3.9813	2.5813
	Mother of normal children	24.17*	1.36290	0.001	-27.4513	-20.8887
Mother of LD children	Mother of ID children	0.70	1.36290	1.000	-2.5813	3.9813
	Mother of normal children	23.47*	1.36290	0.001	-26.7513	-20.1887
Mother of normal children	Mother of ID children	24.17*	1.36290	0.001	20.8887	27.4513
	Mother of LD children	23.47*	1.36290	0.001	20.1887	26.7513

*Significant at 0.001 level

Mothers of children with cerebral palsy had a significantly lower quality of life pattern than mothers of children with normal development or fewer health issues.²⁷⁻²⁹ Puka et al. found in their research that parents of children with childhood-onset epilepsy experience a lower quality of life. The results of our study are consistent with those of earlier studies demonstrating the interdependence of psychological and medical factors, with psychosocial factors having a crucial role in the quality of life and well-being of children and their parents.³⁰ Mothers with disabled children have a lower quality of life than mothers with normally developing children.³¹ The mothers of disabled children have to face various difficulties and challenges, because of which, they are the ones who suffer the most and their physical quality of life declines as a result. All of these can hurt their health. Thus, stress becomes responsible for the decay of their immune system. The results were the same as those of various other studies.^{10,31-33} Not many differences were found between intellectual disabilities and autism groups in the present research. Parents in both groups were found to have these problems, particularly children with intellectual disabilities or autism spectrum disorders seemed to have more stress and a lower quality of life.⁸

Even though there are social support services for mothers, they are not enough to fulfil the high demand. Support should be oriented toward services in social care, financial aid, and easy access to healthcare services.³⁴

Conclusion

The study compared the quality of life of mothers of disabled children and non-disabled children. The result findings showed significant differences between the groups of mothers, which the health practitioners working in the field of rehabilitation process need to be aware of. These findings explore that supportive and therapeutic services for mothers of disabled children are needed to improve their quality of life. Interventions focus must be family-centred, and healthcare professionals should be aware of the bidirectional relationship between disabilities, family

environment, and well-being of children and parents. Mothers' quality of life could be improved by providing the family with emotional and psychological support, along with social, financial and medical support. Mothers caring for children with intellectual and locomotor disabilities have an immediate need for programmes that foster optimism, hope, and well-being and train effective stress management skills.

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