



Quality Of Life Among The Mothers Of Children With Autism Spectrum Disorder

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Abstract

Children with Autism Spectrum Disorder is a major shock for the parents and has distressing effects on social, family, psychological, emotional, economical and interpersonal relationship of the parents. Many factors can influence the quality of life of the parents with ASD challenged children in family.

Objectives:

1. The present study is aimed to assess the quality of life among the mothers of children children's with ASD
2. To determine the association between quality of life and selected demographical variables like age, education, occupation, type of family, area of living, number of children's affected with disability, severity of disability.

Methods: 30 mothers of children with ASD who presented to the Autism Clinic, Victoria Hospital at Kollam from January to March 2025 were enrolled after getting informed consent and study approval. Demographic data of children and mothers in the study group by convenient sampling were entered into a proforma and the mothers were administered with WHO-QOL BREF Questionnaire to assess the Quality of life. Results: The study results were found that mothers had low to moderate Quality of life in all the domains, i.e., physical health, psychological health, social relationship, environmental health. Higher mean score was observed in the social relationship domain. When the educational status of the parent is higher, mothers reported a low Quality of life score, though no such difference was seen with the educational status, occupation of mothers or other variables.

Conclusion: These finding must be taken into account in providing better and more specific supports and interventions for mothers to improving Quality of life. Social support and different coping strategies should be developed to respond positively to individual changing needs of mothers from the stress of having a child with ASD.

Keywords: Mothers of children with Autism Spectrum Disorder, Quality of life

INTRODUCTION

Parenting a child with autism spectrum disorder (ASD) is a deeply rewarding experience, but it also comes with unique challenges that can significantly impact the mental health of parents and caregivers (Ripamonti, 2016; Ripamonti, 2016). Caring for a child with ASD poses significant challenges on a daily basis which can be overwhelming for parents and profoundly affect the well-being of the entire family (Giovagnoli and Postorino, 2015). Many parents face ongoing stress related to managing therapies, advocating for services, navigating social stigma, and coping with uncertainty about their child's future. Parents are in family who deal with the issues associated with child's disability and also maintain the household so it is very important for parents to take some time to care for themselves as individuals and getting enough sleep, eating regular meals, taking a short walk, and doing the things that they really enjoy. Parents having a child with autism experience a variety of stressors and stress reactions related to the child's disability and known to get impacted in many ways because of having a special child. The parents of children with autism experience higher levels of anxiety, depression, and emotional burnout compared to parents of neurotypical children or those with other developmental conditions. Feelings of isolation, financial strain, and disrupted routines can further contribute to emotional distress. These include feeling sad, depression at various stages of life and experiencing other emotional reactions Birth of the special child is a major shock for the parents and has distressing effects on social, family, psychological, emotional, economical and interpersonal relationship of the parents. It affects parenting skills, parenting attitude, which in turn effects the psychological, social, emotional and personality development of the child.

In India, where awareness and support for autism are still evolving, parents often face this journey with limited resources, societal stigma, and significant emotional pressure. While much attention is rightly given to the needs of children with autism, the mental health of their parent. Population-based studies from the India showed that despite greater utilization of services, caregivers of children with ASD were more likely to report difficulties in accessing child healthcare services and have more unmet family support needs as compared to parents of children with other developmental disabilities or typically developing children (Suzumura, 2015).

Indian parents of children with autism frequently encounter high levels of stress, anxiety, and even depression. The constant demands of caregiving, combined with worries about the child's future, financial burdens, lack of inclusive education, and limited access to therapy or support services, can severely impact their emotional and psychological well-being. Furthermore, cultural expectations and the absence of widespread community understanding can lead to feelings of isolation and guilt. The prevalence of autism in India has been significantly increasing the prevalence of autism in India 18 million people in India are diagnosed with autism about 1 to 1.5 percent children aged two to nine years are diagnosed with autism spectrum disorder (World, 2024).

Quality of Life includes the conditions of life resulting from the combination of the effect of complete range of the factors such as those determining health, happiness and a satisfying occupation, education, social and intellectual attainments, freedom of actions and freedom of expression. The concept is further understood as an individual's perception of their position in life in context of the culture and value systems in relation to their goals, expectations, standards and concerns. The quality of life for parents of children with autism spectrum disorder is often significantly impacted due to unique challenges associated with raising a child presence of a child with autism in the family calls for a lot of adjustment on the parents and other family members. Although, the unmet needs of parents of children with autism are universally linked to stress, anxiety and depression there could be some cultural differences in the way this stress impacts parents and their quality of life. In India. Parents with children having autism experience more stress and depression compared to their counterpart who have children with no development disorder. Disabilities of

children may burden their family members, especially their parents, who are their long-term caregivers. Mothers act as the primary caregiver within the family and children with autism may challenge their limitations. Mothers often take on the primary caregiver role which can be physically and emotionally exhausting especially the child required high support.

The purpose of this study is to assess the quality of life among the mothers of children with autism spectrum disorder to determine the association between quality of life. In this study an attempt is made to find out the relationship between and selected demographical variables like age, education, occupation, type of family, area of living, number of children affected with disability, severity of disability.

Methodology

Sample

30 mothers of children with autism spectrum disorder who presented to the Autism Clinic in Victoria hospital at Kollam from January to March 2025. were enrolled after getting informed consent and study approval. Demographic data of children and mothers in the study group by convenient sampling were entered into a proforma and the mothers were administered with WHOQOL BREF Questionnaire to assess the Quality of life. A written informed consent from the parents of the child were taken before commencing the study. Interview was conducted by a single interviewer in a single setting.

Tools used

1. **Personal data sheet:** Personal and socio-demographic information is collected in this sheet.
2. **WHOQOL BREF Questionnaire** to assess the Quality of life.

The WHOQOL-BREF questionnaire developed by the WHOQOL group was used in the present study (World Health Organization 1996). This tool has been widely used considering its good psychometric properties (Derguy, 2018). Permission to use the material was taken from the WHO team before the study (Lekhara, 2014). The WHOQOL-BREF is a self-administered questionnaire that includes 26 items on an individual's health and well-being in the preceding two weeks. It assesses overall QOL (Q1) and general health (Q2). It contains four domains: Physical health (7 items) (D1), Psychological health (6 items) (D2), Social relationships (3 items) (D3), and Environment (8 items) (D4). Responses to questions are on a 1–5 Likert scale where 1 represents 'disagree' or 'not at all' and 5 represents 'completely agree' or 'extremely'. Therefore, the higher scores on WHOQOL-BREF indicate better QOL.

Statistical analysis

The SPSS software was used for statistical analyses descriptive and correlation. The tests were carried out using a significance level of 0.05. Overall scores and domain scores for the WHOQOL-BREF were calculated according to the WHOQOL-BREF manual.

Results

Socio-demographic aspects

Regarding age of mothers, highest percentage 19 (63.4%) in the group between 30-35 years, 6 (20%) belongs the age group of 25 to 30 years and only 5 (16.6%) were at the age above 35 years. With regards to the religion 16 (53.3%) of mothers belongs to Hindus and 8 (26.6%) were Muslims and minimum subjects 6 (20.1%) were Christians. While seeing the education of mother, majority of them 18 (60%) completed their under graduation degree level of education and 12(40%) completed their higher secondary level of education. While portraying the occupation of mother, majority 14 (46.6%) were House wife and 11(36.66%) of them doing private job and 5 (16.74%) were Government employees.

Regarding family income about 12(40) were have income of Rs20, 000/- 30,000/- and 10 (33.34%) were have above Rs30, 000/- income /month and 8 (26.66%) were have Rs10, 000/- 20,000/-income /month. Regarding area of living 15((50%) belongs to the rural background and other half numbers 15(50%) belongs to Urban community. About 24(80%) have 2 children and 6 (20%) have one child. Regarding birth order 18(60%) had one child and 12 (40%) had two children. Regarding level of severity of autism 20 (66.6%) had moderate level and 8 (26.6%) had mild and least numbers 2 (6.8%) had severe autism.

Table 1. Quality of life of Mothers

Quality of life	Frequency (f)	Percent (%)
Low	20	66.6
Moderate	10	34.4
Total	30	100

In this study, researcher found that mothers of children's with autism had low to moderate level of Quality of life in all the domains where majority (66.6%) of mothers' experiences low Quality of life and around 34.6% experiences moderate Quality of life Moreover, Quality of life comprised of physical health, psychological health, social relationship, environmental health.

Table 2. Mean and SD of domains in quality of life

Domains in QOL	Mean	SD
Physical health	16.3	7.6
Psychological health	11.7	4.4
Social relationships	23.43	16.4
Environmental health	23.1	8.2

However, from the above table it is clear that, higher mean score 23.43 (SD=16.4) was observed in the social relationship domain and the least found with psychological health with mean value 11.7 (SD=4.4).

Table 3: Association between quality of life and demographic

Variable	Chi-square	Df	Significance
Education of mother	30.0	2	0.000
Occupation of mother	10.17	3	0.019
Type of family	0.719	1	0.398
Area of living	1.298	1	0.258
No of children	3.478	2	0.178
Level of autism severity	0.349	2	0.842

from the above table it is clear that that there was association between quality of life and various demographic variables such as education of the mother, occupation of the mother, type of family, Area of living, Number of children's and level autism severity.

Discussion and Conclusion

The primary objective of the study was to investigate the Quality of life of mother of children with ASD. The study results indicated that the Mother of children with ASD had significantly lower scores in all the domains of WHOQOL-BREF. Given overall QOL, Mother of children with ASD reported poor QOL. These findings were in similar lines to the previous studies reporting poor QOL in families of children with ASD (Donald, 2018). QOL is a wide concept subjective to an individual's physical-psychological health, level of independence, social ties, personal views, and relationship to conspicuous features of their surroundings in a complex way (Kuhlthau, 2014). As the results of the present study indicated that all of these domains were affected, parents of children with ASD showed overall poorer QOL.

Family is the main source of support for the persons with disabilities in any society. Multiple factors seem to be responsible for poor QOL of mothers of children with ASD. When the educational status of the mother is higher, mothers reported a low Quality of life score, though no such difference was seen with the educational status or occupation of mothers. The results of the study also indicated that self-rated psychological health was poorer than physical health and was affected domain. Although poor psychological health is often linked to increased stress levels in parents raising children with ASD, it has also been related to parental sentiments of loneliness. Additionally, in the Indian scenario, the

concerns about the child's future might have led to grief, emotions of self-blame, guilt, and social humiliation and may negatively impact the psychological health of the mother. Mother responsibilities might limit parental opportunities to dedicate time outside the home and socialize. It has also been reported that stigmatization, more caregiving obligations, and greater financial demands for taking care children with ASD may limit mother capability to socialize and bring positive changes to their environment

These finding must be taken into account in providing better and more specific supports and interventions for mothers to improving Quality of life. Social support and different coping strategies should be developed to respond positively to individual changing needs of mothers from the stress of having a child with disabilities.

Limitation of this study

The present study has a few limitations. The sample was limited to parents who have had contact with professional care center and whose children attended interventions regularly. Further research is warranted to consider the everyday experiences of the families and reach out to those parents who have not sought professional services.

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