E-ISSN: 2664-1305
P-ISSN: 2664-1291
Paediatricnursing: 7-2-6
www.paediatricnursing.net
IJRPN 2025; 7(2): 41-45
Received: 21-05-2025
Accepted: 23-06-2025

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A study to assess the quality of life among caregivers of autistic children in a selected tertiary care hospital in Western Maharashtra

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DOI: https://www.doi.org/10.33545/26641291.2025.v7.i2a.236

Abstract

Introduction: Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition that significantly impacts not only the affected child but also the primary caregivers, often leading to substantial emotional, physical, and social strain. In low-resource settings, caregivers- typically mothers-play a central role in managing the child's needs, which can negatively affect their Quality of Life (QoL). Despite increasing recognition of ASD, caregiver well-being remains underexplored in the Indian context.

Methods: A descriptive cross-sectional study was conducted among 49 primary caregivers of children diagnosed with ASD. Participants were selected using systematic random sampling in a tertiary care hospital. Data was collected using a semi structured sociodemographic questionnaire comprising of socio demographic variables and the standardized Quality of Life in Autism-Parent Version (QoLA-P), which assessed both general QoL and the impact of ASD symptoms on daily life.

Results: The study revealed that 42.9% of caregivers experienced low QoL, 38.8% had moderate QoL, and only 18.4% reported high QoL. A statistically significant association was observed between QoL and the duration of the child's illness ($p< 0.05$), suggesting prolonged caregiving contributes to increased burden.

Discussion: The study underscores the multidimensional challenges faced by caregivers of children with ASD. Factors such as prolonged caregiving, lack of social support, and emotional exhaustion contribute to diminished QoL. These findings highlight the urgent need for caregiver-centered interventions, psychosocial support programs, and policy-level initiatives to address caregiver well-being.

Conclusion: Caregivers of children with ASD face considerable challenges that adversely affect their quality of life. Incorporating caregiver support into autism care frameworks is essential to enhance both caregiver and child outcomes. Routine assessment of caregiver well-being should be integrated into pediatric neurodevelopmental services.

Keywords: Autism spectrum disorder (ASD), caregiver burden, parental quality of life, neurodevelopmental disorders, roy's adaptation model, pediatric caregiving, psychosocial stress, quality of life in autism (QoLA-P)

Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental condition marked by persistent challenges in communication, social interaction, and the presence of restricted, repetitive behaviors or interests, typically manifesting in early childhood. Globally, ASD prevalence is estimated at around 1 in 100 children [10]. In Asia, it ranges from 0.15% to 1.1%, influenced by diagnostic practices and healthcare accessibility [8]. An Indian multicentric study reported that approximately 1 in 100 children aged 2-9 years may be affected by ASD [5]. Management of ASD requires continuous, multidisciplinary interventions, including behavioral therapies, speech and language therapy, occupational support, and structured educational programs. While clinical care primarily focuses on the child, the broader impact significantly affects the family unit, especially primary caregivers, who play a pivotal role in daily care and therapeutic engagement.

Caregivers of children with ASD encounter distinct challenges that differentiate their experiences from caregivers of children with other chronic or developmental conditions. The unpredictable behaviours, difficulties in communication, and need for structured routines contribute to substantial psychological and physical strain.

These caregiving demands often lead to increased levels of stress, anxiety, depression, and social withdrawal. Furthermore, societal stigma and lack of awareness regarding ASD can result in misjudgement and isolation, compounding caregiver distress. The caregiver's role extends beyond parenting to include responsibilities of a therapist, advocate, educator, and case manager, highlighting the critical need to support their well-being.

Background

Globally, studies have demonstrated that caregivers of children with developmental disabilities report significantly poorer health outcomes compared to the general population [5]. A study done by Brehaut & *et al*. found increased risks of musculoskeletal disorders, sleep disturbances, and chronic illnesses such as type 2 diabetes among these caregivers. Similar trends have been observed in low-resource settings [1]. For instance, in South Africa, 36% of caregivers reported difficulty balancing caregiving with employment and home responsibilities [3]. In Nepal, caregivers expressed moderate to severe stress linked to inadequate therapy access and limited support networks [4]. The unique caregiving burden associated with ASD, characterized by behaviour regulation difficulties, communication barriers, and the need for rigid routines, further exacerbates stress, often surpassing levels observed in other paediatric conditions.

In the Indian context, caregiving challenges are intensified by cultural expectations, stigma, and uneven access to specialized services. A study conducted by Singh *et al.* (2022) in New Delhi found that caregivers of children with neurodevelopmental disorders had higher prevalence of unmanaged hypertension and diabetes, frequently neglecting their own health due to caregiving obligations [7]. These caregivers often exhibit poor health-seeking behaviour and experience social isolation, especially when compounded by financial strain and lack of structured support systems.

Despite growing recognition of the burden faced by caregivers, their quality of life remains an under-researched area, particularly in tertiary care settings of Western Maharashtra. There is a pressing need for local evidence to inform holistic, family-centered care models that address caregiver stressors and provide effective support. Therefore, this study aims to assess the quality of life among caregivers of autistic children attending a tertiary care hospital in Western Maharashtra and to identify the key challenges and support needs that can guide future caregiver-centered policies and interventions.

Methodology

A descriptive cross-sectional study design was employed to assess the level of quality of life (QoL) among caregivers of children diagnosed with Autism Spectrum Disorder (ASD). The study was conducted at the Early Intervention Centre of a tertiary care hospital in Pune, Maharashtra. The target population consisted of primary caregivers, including parents or guardians, who were directly involved in the care of children with ASD. A systematic random sampling technique was used to select eligible participants who met the inclusion criteria. Based on previous literature and feasibility, a total of 49 caregivers were recruited for the study.

Participants were included if they were primary caregivers of children formally diagnosed with ASD and were willing to provide informed consent. Caregivers with a diagnosed psychiatric disorder that could interfere with their participation and families of children with additional severe disabilities other than ASD were excluded. Written informed consent was obtained from all participants prior to data collection.

Data was collected through face-to-face interviews conducted in a private setting in the Early Intervention Centre to ensure confidentiality and comfort. Each interview session lasted approximately 20 to 25 minutes. A structured questionnaire was used for data collection, which comprised two sections:

- First section comprised of socio-demographic information about the caregiver (such as age, gender, marital status, education, occupation, and family type) and clinical details of the child (such as age, gender, and duration of illness).
- Second section included the Quality of Life in Autism - Parent Version (QoLA-P), a standardized and autism-specific tool developed by Eapen *et al*. (2014) [2]. The QoLA-P consists of two parts:
- ▪ Part A (28 items) evaluates general perceived QoL across emotional, physical, social, and financial domains.
- ▪ Part B (20 items) assesses QoL impact specifically due to the child's ASD symptoms.

Items were rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores in Part A indicated better QoL, whereas higher scores in Part B indicated lesser negative impact of ASD symptoms.

The tool was validated and reliable, with Cronbach's alpha values of 0.94 for Part A and 0.89 for Part B [2]. A pilot study was conducted on 10% of the sample to assess clarity, feasibility, and reliability, with minor revisions made based on feedback before initiating full-scale data collection.

Results

The data was analyzed using SPSS version 18. Descriptive statistics, including frequency, percentage, mean, and standard deviation, were used to summarize the data. Chi-square tests were used to determine associations between caregiver burden and selected demographic and clinical variables. A p-value less than 0.05 was considered statistically significant.

Table 1: Distribution of Sample as per perceived QOL of Caregivers, (n=49)

Criteria measure of perceived QOL score		
Level of Scores	**Percentage**	**Frequency**
High QOL	18.4%	9
Moderate QOL	38.8%	19
Low QOL	42.9%	21
Criteria measure of QOL due to impact of ASD symptoms		
High QOL	14.3%	7
Moderate QOL	14.3%	7
Low QOL	71.4%	35

The table 1 shows that on Part A, 42.9% of caregivers (n=21) reported low QoL, 38.8% (n=19) had moderate QoL, and only 18.4% (n=9) reported high QoL, indicating that the majority (81.7%) experienced low to moderate well-being, reflecting emotional strain, caregiver fatigue, and unmet support needs. In Part B, which evaluates QoL specifically affected by ASD symptoms, a significant 71.4% of caregivers (n=35) reported low QoL, while only 14.3% (n=7) each reported moderate and high QoL. These findings underscore the profound impact of caregiving responsibilities and ASD-related behavioral challenges on caregiver well-being, highlighting the need for targeted interventions, including psychological support, respite care, and community-based assistance programs.

Table 2: Demographic data of children and Association with perceived QOL, (n=49)

Variables	Categories	Percentage (%)	Frequency (f)	Levels of Perceived QOL			Association with Perceived QOL Score		Result
				High	Moderate	Low	Chi Test	P Value	
Age of Child	1-3 years	16.3%	8	2	3	3	1.603	0.205	NS
	3-6 years	51.0%	25	3	11	11			
	6-12 years	32.6%	16	4	5	7			
Gender of child	Male	81.6%	40	8	15	17	0.414	0.52	NS
	Female	18.4%	9	1	4	4			
Duration of illness	1-3 years	57.1%	28	3	14	11	6.605	0.01	S
	3-6 years	30.6%	15	5	2	7			
	6-12 years	12.2%	6	1	3	3			
Severity	Mild	87.8%	43	8	18	16	2.892	0.08	NS
	Moderate	12.2%	6	1	1	5			

Table 2 depicts the demographic data of children, out of the total sample of 49 the majority of children i.e. 51% were in the age group of 3-6 years, followed by 32.6% in the age group of 6-12 years, 16.3% in the age group of 1-3 years and the least. Most children had been diagnosed for 1-3 years (57.1%), followed by 3-6 years (30.6%), and 6-12 years (12.2%). The severity of illness was documented as per the medical records and were classified into mild, moderate and severe as per ISAA scale. Out of 49 children the majority had mild symptoms i.e 43 (87.8%), followed by 6 (12.2%) with moderate symptoms.

Association of selected socio-demographic variables with quality of life was conducted using Chi square test. The table shows that among the child-related variables, the duration of illness was found to have a statistically significant association with the caregiver's perceived quality of life ($p = 0.01$). Caregivers of children diagnosed with ASD for longer durations reported lower QoL, possibly due to the cumulative emotional, physical, and financial strain experienced over time. However, other child-specific variables such as age, gender, and severity of ASD symptoms did not show a statistically significant relationship with perceived QoL or QoL related to the impact of ASD symptoms ($p > 0.05$), indicating that these factors alone may not substantially alter caregiver well-being.

Table 3: Demographic details of the caregiver and Association with QOL due to impact of ASD symptoms, (n=49)

Variables	Category	Percent (%)	Frequency (f)	Levels of Perceived QOL			Association with QOL due to impact of ASD Symptoms Score		Result
				High	Moderate	Low	Chi Test	P Value	
Relationship with child	Mother	93.8%	46	6	6	34	2.27	0.13	NS
	Father	6.1%	3	1	1	1			
Age of Caregiver	20-40 years	95.9%	47	6	6	34	2.27	0.13	NS
	40-60 years	4.1%	2	1	1	1			
Education	10+2	30.6%	15	2	1	12	1.47	0.22	NS
	Graduation and above	69.4%	34	4	7	23			
Occupation	Govt job	8.2%	4	1	1	2	6.96	0.008	S
	Private	8.2%	4	2	1	1			
	Home Maker	83.6%	41	4	5	32			
Health Issues or undergoing any treatment	Yes	14.3%	7	1	1	5	0.000	1.000	NS
	No	85.7%	42	6	6	30			
Disability in other Children	NA	40.8%	20	1	4	16	5.13	0.02	S
	Yes	2.0%	1	1	1	1			
	No	57.1%	28	5	2	18			

Table 3 shows demographic profile of caregivers of autistic children in the present study reveals that the majority were mothers (93.9%) highlighting the gendered nature of caregiving roles. Most caregivers were in the age group of 20-40 years (95.9%). In terms of education, the majority (69.4%) had completed graduation or higher education, and most (83.7%) were homemakers, indicating that caregiving often coexists with domestic responsibilities. 14.3% of caregivers had existing health issues or were undergoing treatment, indicating potential vulnerabilities in caregiver well-being. A significant portion reported no disabilities in other children (57.1%), while 40.8% marked this as not applicable as they had no other children or dependents.

Regarding caregiver-related factors, the study found that most variables-including caregiver age, gender, education level, health status, and relationship to the child were not significantly associated with either perceived quality of life (QoL) or the impact of ASD symptoms on QoL ($p > 0.05$). However, caregiver occupation was significantly associated with QoL related to the impact of ASD symptoms ($p = 0.008$), with homemakers reporting lower QoL scores compared to those employed in private or government sectors, suggesting that employment may offer protective factors such as social interaction, financial stability, and mental engagement that help mitigate caregiving stress. Additionally, a statistically significant association was found between the presence of disability in other children and caregiver QoL related to ASD symptom impact (p = 0.02), indicating that caregivers managing multiple children with disabilities experienced heightened stress and poorer QoL. Other family-related variables such as number of dependents, and availability of a support system did not show statistically significant associations, though trends suggested that lack of support and greater caregiving burdens may negatively influence QoL. In summary, the study identified duration of illness, caregiver occupation, and disability in other children as key factors with statistically significant associations to caregiver QoL.

Discussion

The present study aimed to assess the quality of life (QoL) among caregivers of children diagnosed with Autism Spectrum Disorder (ASD) and to examine its association with selected socio-demographic variables. The findings clearly demonstrate that a significant proportion of caregivers experience compromised well-being. As revealed by Part A of the QoLA tool, 42.9% of caregivers had low QoL and 38.8% had moderate QoL, with only 18.4% reporting high QoL. These results suggest that the majority of caregivers face moderate to severe challenges across emotional, physical, and social domains. The mean QoL score of 89.18 indicates an overall moderate level of functioning, though the emotional strain of caregiving persists for most.

Part B of the QoLA tool, which specifically assesses the impact of ASD-related symptoms on caregiver QoL, revealed even greater distress: 71.4% of caregivers reported low QoL due to ASD symptoms. This suggests that behaviors such as communication difficulties, erratic routines, and social challenges significantly disrupt caregivers' daily lives. These findings align with those of previous studies conducted by Renford *et al.*, 2020 and Ten Hoopen *et al.*, 2022, which identified caregiving for children with ASD as more emotionally taxing than caring for children with other developmental or physical disorders [6, 9].

While most socio-demographic variables, including caregiver age, gender, education, marital status, and health status, showed no statistically significant association with QoL, certain factors were notably impactful. Occupation emerged as a significant variable (p = 0.008), with homemakers reporting significantly lower QoL compared to caregivers employed in private or government sectors. This may be attributed to the protective effect of employment, which offers financial independence, social interaction, and structured routine. Similarly, a statistically significant association was found between the presence of disability in other children and caregiver QoL related to ASD symptom impact (p = 0.02), highlighting the compounded burden faced by families managing multiple caregiving roles.

The duration of the child's illness was also found to be significantly associated with caregiver QoL (p = 0.01). Caregivers of children diagnosed for over three years reported lower QoL, possibly due to prolonged emotional and physical fatigue. These results support the growing body of literature emphasizing the need for sustained interventions and support systems for long-term caregivers. While variables such as type of family, number of dependents, and presence of a support system were not statistically significant, trends suggested that caregivers with fewer dependents and some form of social support reported better QoL.

Overall, the study reinforces the critical need to integrate caregiver well-being into autism care strategies. As supported by literature and the present findings, tailored interventions, such as structured counselling, parent training modules, peer support groups, and stress management programs should be incorporated into both hospital and community-based settings. Given that emotional resilience and support systems play a pivotal role in caregiver QoL, addressing these needs will not only enhance the well-being of caregivers but also improve developmental outcomes for children with ASD.

The generalizability of the study findings is limited, as the participants were drawn exclusively from an urban setting in India.

Conclusion

In conclusion, the study highlights that caregivers of children with Autism Spectrum Disorder (ASD) face significant challenges that adversely affect their quality of life, particularly due to the impact of ASD-related symptoms. While most socio-demographic factors showed no significant association, key variables such as duration of illness, caregiver occupation, and presence of disability in other children were significantly linked to lower QoL outcomes. These findings underscore the need for targeted interventions that support caregiver well-being through structured counseling, social support systems, and community-based resources. Addressing caregiver burden as an integral component of autism care is essential to ensure both caregiver resilience and optimal developmental outcomes for children with ASD.

Conflict of Interest

Not available.

Financial Support

Not available.

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How to Cite This Article
Abraham ML, Sunny CS, Dhaka S, Devipriya. A study to assess the quality of life among caregivers of autistic children in a selected tertiary care hospital in Western Maharashtra. International Journal of Research in Paediatric Nursing. 2025; 7(2): 41-45.