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Quality Of Life Among Primary Caregivers Of Children With Autism Spectrum Disorder In A Rehabilitation Centre

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ABSTRACT

INTRODUCTION: Autism Spectrum Disorder (ASD) places substantial physical, emotional, and social demands on primary caregivers, often diminishing their quality of life (QoL). This, in turn, affects both caregiver well-being and child development. Assessing caregiver QoL in rehabilitation centers is crucial to guide supportive interventions and family-centered care. **AIM:** To assess the quality of life among primary caregivers of children with autism spectrum disorder attending a rehabilitation centre. **OBJECTIVES:** 1) To assess the quality of life among primary caregivers of children with autism spectrum disorder. 2) To determine the association between selected demographic variables among primary caregivers of children with autism spectrum disorder and their quality of life. **MATERIALS AND METHODS:** This descriptive study assessed the quality of life (QoL) among 60 primary caregivers of children (1–18 years) with ASD in a rehabilitation centre at Kanyakumari District. Data were collected via structured interview schedule using structured questionnaire for demographic variables and the ASD Parent/Caregiver QoL Questionnaire for quality of life. QoL was analyzed with descriptive statistics, and associations with demographics were tested using Chi-square. **FINDINGS:** Most primary caregivers of children with ASD reported moderate QoL (76.7%), with poorer QoL linked to child-related factors such as multiple disabilities, family history of ASD, and consanguineous marriage. These findings stress the need for targeted psycho-social support and genetic counseling to improve primary caregiver well-being. **CONCLUSION:** The study concluded that most primary caregivers of children with ASD had moderate QoL. Targeted psycho-social support, family-centered care, and genetic counseling are essential to improve primary caregiver QoL and child outcomes.

Keywords: Autism Spectrum Disorder, Primary Caregivers, Quality of Life, Rehabilitation Centre, Caregiver well-being, Child Disabilities, Family Support.

INTRODUCTION

Caregiving for children with autism spectrum disorder (ASD) is often described as navigating a labyrinth of emotional, social, and physical challenges, where the caregiver's own quality of life (QoL) frequently takes a back seat. In the crucible of daily responsibilities, primary caregivers especially mothers bear the brunt of the caregiving load, grappling with fatigue, chronic pain, and emotional weariness that cast a long shadow over their well-being.

In a nation like India where cultural stigma and resource constraints frequently compound parental strain, report that caregivers endure physical ailments such as chronic pain, ulcers, and fatigue, emphasizing that caregiving burdens in South Asia are intensified by systemic hurdles and a dearth of support infrastructure. **(Biswal and Pathak, 2025)**

Indeed, a comprehensive integrative review synthesizes data from over 5,500 parents, revealing that caregivers of individuals with ASD show significantly lower quality of life across physical, psychological, social, and spiritual domains compared to non-caregivers, with the severity of the child's symptoms emerging as the most potent predictor of diminished well-being. **(Turnage and Conner, 2022)**

Mirroring this trajectory, employed a structural equation modeling to delineate how maladaptive coping strategies, impaired family functioning, and deficient perceived social support mediate the effect of ASD severity on caregiver quality of life, highlighting psychosocial dynamics as pivotal in the caregiving equation. **(Ten Hoopen et al., 2022)**

Further a field, the largest survey of its kind found that formal social support from rehabilitation institutions notably improved the physical and mental quality of life among caregivers, particularly men, thereby underscoring how systemic interventions can serve as critical lifelines even in high-pressure caregiving scenarios. **(Ran et al., 2023)**

Taken together, extant literature underscores a clear narrative: caregivers of individuals with ASD routinely endure compromised quality of life rooted not solely in demographic or socio-economic variables, but deeply entrenched in the severity of the child's condition, coping mechanisms, familial dynamics, and the availability (or absence) of formal support systems. In such a context, findings from the present study, conducted within the unique socio-cultural landscape of Kanyakumari district, are timely and critically needed to shine a light on the often-unseen struggles among primary caregivers and to inform culturally sensitive, sustainable interventions.

Significance and Need for the Study

Primary caregivers of children with autism spectrum disorder (ASD) play a crucial role in the management, rehabilitation, and overall development of their children. However, caregivers of children with ASD experience significantly lower quality of life (QoL) compared to caregivers of typically developing children, with high levels of stress, anxiety, and role burden **(Majic et al., 2023; Ogston et al., 2021).** This reduced QoL affects not only the caregivers themselves, but also the effectiveness of care they provide, ultimately influencing the child's developmental outcomes.

Parenting stress is strongly associated with reduced well-being, particularly when ASD related challenges are present **(Hastings et al., 2022).** Intolerance of uncertainty further exacerbates caregiver burden and negatively impacts QoL **(Gomez-Rico et al., 2022),** while poor sleep among caregivers is also linked to diminished health and functioning **(Liu et al., 2021).** These findings suggest that multiple modifiable factors contribute to caregiver stress and addressing that could significantly enhance caregiver well-being.

Rehabilitation centers represent key points of contact for families of children with ASD, offering structured interventions and professional support. Evidence suggests that family-centered and supportive care models improve caregiver QoL and overall family functioning **(Bonis, 2022; Khanna et al., 2021)**. Furthermore, interventions that provide social and professional support have been shown to alleviate caregiver burden and improve outcomes **(Lai & Oei, 2022)**. Importantly, improvements in caregiver QoL may also be associated with better child outcomes, as seen in family-centered applied behavior analysis (ABA) programs. **(Ravenscroft et al., 2023)**

The need for this study is underscored by the lack of systematic assessment of caregiver QoL in rehabilitation centre settings, particularly in low-resource contexts. Recent validations of caregiver QoL measures provide reliable tools for this purpose **(Khanna et al., 2021).** However, the socio-economic disparities and gaps in caregiver support remain unaddressed. **(Murray et al., 2022)**

Gunavathy K, Raja P, and Umadevi, 2025 conducted a cross-sectional study at Government Medical College, Karur, Tamil Nadu among children between 1–12 years attending a pediatric OPD. The study found an ASD prevalence of 6.1% (1 in ~16 children), with a higher prevalence in males (8.3%) compared to females (3.0%) and especially it was more prevalent among children older than 3 years. Additionally, the study identified associated factors such as higher socio-economic status, increased parental age, and excessive screen time (mobile/TV use >1 hour daily).

Robert. N. G. et al., (2021) conducted a study on quality of life (QoL) among caregivers of children with Autism Spectrum Disorder in Tamil Nadu, South India. A quantitative research approach with a non-experimental descriptive cross-sectional design was used. A total of 120 caregivers of children with Autism Spectrum Disorder were selected. The WHOQoL-BREF was employed to assess the caregivers' quality of life.

The study reported that 59.1% of the caregivers had poor QoL in the psychological domain, and 56.6% had poor QoL in the physical domain. However, in the social and environmental domains, caregivers demonstrated an average QoL, accounting for 42.5% and 45%, respectively. Caregivers' QoL, based on the duration of childcare, showed a significant difference in the psychological and environmental domains. No significant difference was found in the caregivers' QoL based on age in the environmental domain.

The investigator during her professional experience among the primary care givers with ASD found that they often experience emotional stress, financial strain and lack of social support that interrupts their quality of life. Therefore, this study is significant because it will: assess the multi-dimensional challenges faced by caregivers of children with ASD in a rehabilitation centre context, identify factors contributing to reduced QoL, including stress, uncertainty, and lack of support and provide evidence to inform the development of family-centered interventions and supportive services within rehabilitation centers. By focusing on caregiver QoL, this study will not only contribute to the well-being of families but also enhance the effectiveness of rehabilitation outcomes for children with ASD.

Given this background, the present study seeks to shed light on the unsung struggles of primary caregivers by assessing their quality of life and examining its association with selected demographic factors. By doing so, it aims to bridge the gap in literature and provide evidence that could serve as a stepping stone for targeted interventions, ensuring that caregivers are not left in the lurch but are supported in their caregiving journey.

Statement of the Problem

A descriptive study to assess the quality of life among primary caregivers of children with autism spectrum disorder in a rehabilitation centre at Kanyakumari district.

Objectives of the study

- To assess the quality of life among primary caregivers of children with autism spectrum disorder.
- To determine the association between selected demographic variables among primary caregivers of children with autism spectrum disorder and their quality of life.

Research Methodology

The conceptual framework of this study was based on the pender's health promotion model. A quantitative research approach with a descriptive research design was employed to evaluate the quality of life among primary caregivers of children with autism spectrum disorder (ASD) who attended the Rehabilitation Center. The study was conducted in Gerdi Gutperle Agasthiyar Muni Rehabilitation Center at Kanyakumari district. A total of 60 primary caregivers of children with ASD were selected as study participants using a non-probability convenience sampling technique. Informed written consent was obtained from all the participants.

Ethical clearance was secured, and prior permission was obtained from the managing director of the rehabilitation center.

The inclusion criteria comprised children of both genders within the age range of 1–18 years, while children with Down syndrome, attention deficit hyperactivity disorder (ADHD), or intellectual disability were excluded to ensure a homogeneous sample specific to ASD. Data were collected using a structured interview schedule, which consisted of two sections. Section A captured demographic information of both primary caregivers and their children, including age, education, occupation, income, type of family, and child-specific characteristics. Section B included the standardized Autism Spectrum Disorder Parent/Caregiver Quality of Life Questionnaire (ASDPC-QoL), a 5-point Likert scale ranging from 1 (Never) to 5 (Always), measuring mental, physical, social, and caregiver-related domains. The total score was categorized into poor (1–46), moderate (47–93), and good (94–140) quality of life.

Data collection was conducted through direct structured interviews, which facilitated accurate responses, particularly among participants with limited literacy. The collected data were analyzed using descriptive statistics (frequency, percentage, mean, and standard deviation) to summarize the quality-of-life outcomes, while inferential statistics (Chi-square test) were applied to examine associations between selected demographic variables and caregiver quality of life. This approach provided a comprehensive understanding of both the profile of caregivers and the factors influencing their quality of life.

Major Findings The findings of the study were presented based on the objectives.

Demographic Variables

Demographic profile among primary caregivers of children with autism spectrum disorder.

The majority of primary caregivers were in the age group of 31–40 years (36.7%), followed by 41–50 years (26.7%) and 21–30 years (20%). Only 11.7% were aged 51–60 years, while a small proportion (5%) were above 60 years. With regard to education, 45% of mothers had school-level education, 41.7% were graduates and above, and 13.3% had non-formal education, indicating that nearly half of the mothers possessed at least secondary-level education.

In terms of occupation, the largest group comprised homemakers (45%), followed by private employees (18.3%), self-employed (15%), coolie workers (11.7%), and government employees (10%). With respect to family monthly income, 23.3% of the families earned between ₹ 10,001–20,000, 20% between ₹ 20,001–30,000, and 16.7% had earnings of ₹10,000 or below. About 15% earned between ₹ 30,001–40,000, 11.7% between ₹40,001–50,000, and 13.3% reported an income of ₹ 50,001 and above. This distribution reflects moderate economic diversity among the families.

Regarding family structure, nearly half of the mothers (48.3%) lived in nuclear families, 38.3% in joint families, and 13.3% in extended families. The marital status of the majority was married (86.7%), while 8.3% were unmarried and 5% divorced. Residence-wise, the distribution was almost equal, with 51.7% from rural areas and 48.3% from urban areas.

In terms of religion, half of the mothers were Hindu (50%), followed by Christian (30%), Muslim (15%), and others (5%). The relationship of the caregiver revealed that in most cases, mothers were the primary caregivers (76.7%), while fathers (10%), grandparents (8.3%), and others (5%) played smaller roles.

A family history of autism spectrum disorders was reported by 11.7% of the mothers, whereas 88.3% had no such history. History of consanguineous marriage was present in 20% of participants and absent in 80%.

Demographic profile of children with autism spectrum disorder.

The age distribution of children showed that the largest group was between 6.1–12 years (30%), followed by 3.1–6 years (25%) and 12.1–18 years (20%). Smaller proportions were in the age categories of 1.1–3 years (13.3%), above 18 years (8.3%), and below 1 year (3.3%). This indicates that the majority of children with autism spectrum disorders in the study were in the school-going age group.

With respect to gender, a larger proportion were male (65%) compared to female (35%), reflecting the commonly reported higher prevalence of autism in boys. Regarding birth order, 38.3% of the children were first-born, 35% were second-born, 15% were third-born, and 11.7% were fourth-born or higher.

Regarding treatment, 30% of the children were on medication, while 70% were not. More than half of the children (56.7%) were undergoing speech therapy, whereas 43.3% had not received speech therapy. With respect to multiple disabilities, 18.3% of the children had additional disabilities, while the majority (81.7%) did not have any additional disabilities.

The first objective of the study was to assess the quality of life among primary caregivers of children with autism spectrum disorder

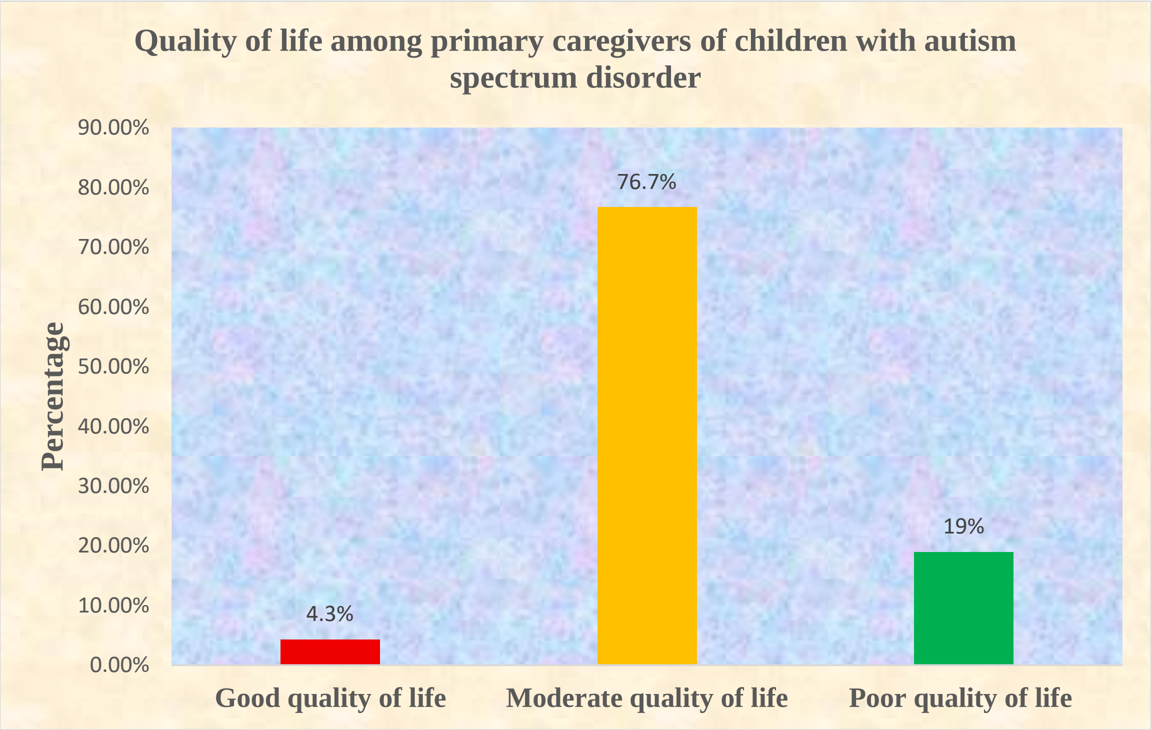

Fig: 1 Distribution of quality of life among primary caregivers of children with autism spectrum disorder.

In the present study, the majority of primary caregivers (76.7%) reported a moderate quality of life, while 19% reported poor quality of life and only 4.3% reported good quality of life. These findings are consistent with earlier research conducted by **Gupta et al., 2022** in India, which revealed that caregivers of children with autism spectrum disorder experience considerable caregiving burden, leading to impaired quality of life across physical, psychological, and social domains.

The findings are congruent with the study conducted by Khaoula Khemakhem. K, et al., (2020) to investigate the quality of life and among caregivers of children with autism spectrum disorders. The Short Form-36 Health Survey Questionnaire was used to assess the quality of life among the caregivers. The findings revealed that 60.7% of caregivers had impaired quality of life and emphasized the link between anxiety, depression and impaired quality of life among caregivers of children with autism spectrum disorders. It spotlights the need for early interventions to assist the caregivers in enhancing their quality of life.

The second objective of this study was to determine the association between selected demographic variables among primary caregivers of children with autism spectrum disorder and their quality of life.

The association between selected demographic variables and the quality of life (QoL) among primary caregivers of children with autism spectrum disorder was analyzed using the chi-square test. The results revealed that mother's age (χ^2 =3.24, df=4, p=0.517), mother's education (χ^2 =1.87, df=2, p=0.392), occupation (χ^2 =4.62, df=4, p=0.328), monthly family income (χ^2 =6.12, df=5, p=0.293), type of family (χ^2 =2.71, df=2, p=0.258), marital status (χ^2 =1.16, df=2, p=0.561), area of residence (χ^2 =0.85, df=1, p=0.356), religion (χ^2 =2.64, df=3, p=0.450), relationship of caregiver (χ^2 =5.42, df=3, p=0.143), child's age (χ^2 =7.02, df=5, p=0.219), gender of child (χ^2 =1.22, df=1, p=0.268), birth order of child (χ^2 =3.88, df=3, p=0.274), medication management (χ^2 =2.54, df=1, p=0.111), and speech therapy (χ^2 =1.37, df=1, p=0.242) did not show any statistically significant association with QoL ($p>0.05$). However, a significant association with QoL was observed for family history of ASD (χ^2 =6.95, df=1, p=0.008), consanguineous marriage (χ^2 =4.87, df=1, p=0.027), and presence of multiple disabilities in the child (χ^2 =9.31, df=1, p=0.002), indicating that these factors significantly influence the primary caregiver's quality of life.

The present study examined the association between maternal and child demographic variables and the quality of life among primary caregivers of children with autism spectrum disorder (ASD). Findings revealed that most socio-demographic variables such as maternal age, education, occupation, monthly family income, marital status, and type of family were not significantly associated with their quality of life. This indicates that quality of life among these mothers is more likely influenced by caregiving demands and child-related factors rather than their personal or socioeconomic background. Similar findings were reported by Abidin et al. (2020), who emphasized that parenting stress and child functional difficulties have a greater impact on maternal well-being than socio-demographic differences.

However, a significant association was observed between the presence of multiple disabilities in the child and maternal quality of life. Mothers whose children had co-occurring disabilities reported poorer quality of life compared to those without such conditions. This finding is supported by Eapen et al. (2021), who highlighted that co-morbidities in children with ASD substantially increase parental stress and reduce overall well-being. Likewise, family history of ASD showed a significant link with poor quality of life, possibly due to compounded caregiving burdens and heightened concerns about genetic risks. In line with this, Almansour et al. (2022) found that families with more than one member affected by neuro-developmental disorders experience greater psychosocial distress and lower quality of life.

Additionally, consanguineous marriage was significantly associated with lower maternal quality of life. This may be attributed to the higher risk of neuro- developmental conditions among offspring in consanguineous unions, thereby intensifying caregiving challenges. A recent study by Khan et al. (2022) in South Asia also reported that consanguinity was linked to increased prevalence of developmental disorders, which in turn negatively impacted family quality of life.

Overall, the findings underscore that while general demographic factors may not strongly influence maternal quality of life, child-specific conditions (such as multiple disabilities) and familial risk factors (family history of ASD and consanguinity) are crucial determinants. This highlights the need for targeted psychosocial interventions and genetic counseling to support mothers of children with ASD.

Nursing Implications

The findings of this study have important implications for nursing practice, education, administration, and research.

Nursing Practice

- Nurses play an important role in supporting primary caregivers of children with autism spectrum disorder by providing counseling, stress management techniques, and emotional support to improve their quality of life.
- Health education programs shall be organized to enhance caregivers' knowledge regarding symptom management, behavioral strategies, and home-based interventions for autistic children.
- Community health nurses shall act as advocates, bridging the gap between families and rehabilitation services, ensuring timely referral and follow-up.

Nursing Education

- Nursing curricula shall incorporate modules on autism spectrum disorders and caregiver well-being, equipping students with the skills needed to assess and support families effectively.
- Continuing education workshops shall help practicing nurses develop competencies in holistic family-centered care for children with developmental disorders.

Nursing Administration

- Nurse administrators shall develop policies to integrate caregiver assessment into routine pediatric and psychiatric care, ensuring that the needs of both the child and the caregiver are addressed.
- Support groups and caregiver training sessions can be initiated within hospital and community settings to provide ongoing assistance.

Nursing Research

- The study provides a basis for further research on interventions to enhance caregiver quality of life, including stress reduction programs, mindfulness, and social support interventions.
- Comparative studies shall be conducted in different cultural and geographical settings to identify universal and region-specific caregiver challenges.

Recommendations

- Further studies shall be conducted with larger samples across different districts and states to generalize findings.
- Intervention studies focusing on caregiver training, stress management, and resilience-building strategies should be undertaken.
- Comparative studies shall be carried out between caregivers of children with autism and caregivers of children with other chronic conditions.

CONCLUSION

The present study concludes that the majority of primary caregivers of children with autism spectrum disorder experience only a moderate quality of life, reflecting the considerable psychological, social, and physical demands associated with caregiving responsibilities. Although most socio-demographic factors such as maternal age, education, occupation, income, marital status, and type of family did not exhibit a significant association with caregiver well-being, child-related variables including the presence of multiple disabilities, family history of ASD, and consanguineous marriage were found to have a statistically significant negative impact on quality of life. These findings suggest that the burden of caregiving is shaped less by socioeconomic circumstances and more by the compounded challenges arising from genetic predisposition, developmental comorbidities, and culturally rooted practices such as consanguinity, thereby underscoring the importance of targeted psychosocial support, genetic counseling, and multidisciplinary interventions. Consequently, the study highlights the urgent need for nursing professionals, rehabilitation specialists, and policymakers to develop comprehensive caregiver-focused strategies that not only address the clinical needs of children with ASD but also strengthen the coping capacity, emotional resilience, and overall well-being of their primary caregivers.

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Conflict of interest statement

The author/ researcher declares that there are no conflicts of interest concerning this research work or its publication.

Ethical statement

The study was conducted after obtaining ethical approval from the institutional ethical committee of St. Xavier's Catholic College of Nursing.

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