PERCEIVED BURDEN AND ITS EFFECT ON QUALITY OF LIFE IN CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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KEYWORDS

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ABSTRACT:

Background: Caregivers of children with Autism Spectrum Disorder (ASD) often experience significant physical, emotional, and psychological burdens due to the nature of the condition. These burdens can profoundly affect their quality of life (QoL), which in turn can impact their ability to provide optimal care. This study aimed to assess the caregiver burden and its relationship with QoL among caregivers of children with ASD.

Materials and Methods: A cross-sectional study was conducted involving 100 primary caregivers of children diagnosed with ASD, aged 3-18 years. The Zarit Burden Interview (ZBI) was used to assess caregiver burden, while the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire was used to evaluate QoL across four domains: physical health, psychological health, social relationships, and environmental health. Statistical analysis was performed using Pearson's correlation and regression analysis to determine the association between caregiver burden and QoL.

Results: The study found that the majority of caregivers experienced moderate to high levels of burden. A significant negative correlation was observed between caregiver burden and all QoL domains ($p < 0.05$). The strongest correlation was found in the social relationships domain ($r = -0.61$, $p < 0.001$). Regression analysis revealed that factors such as higher caregiver burden, unemployment, and lower educational levels were predictors of poorer QoL.

Conclusion: The findings highlight the substantial burden faced by caregivers of children with ASD and its detrimental effect on their quality of life. Interventions aimed at reducing caregiver burden, such as mental health support, respite care, and community-based support programs, are crucial. Policies to address these needs could significantly improve both the caregivers' well-being and the care provided to children with ASD.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by persistent deficits in social communication, restricted interests, and repetitive behaviors [1]. The prevalence of ASD has been increasing worldwide, with the Centers for Disease Control and Prevention (CDC) estimating that 1 in 36 children in the United States is diagnosed with ASD [2]. Similarly, global estimates by the World Health Organization (WHO) suggest that 1 in 100 children is affected [3]. Due to the lifelong nature of ASD, caregivers—particularly parents—experience significant psychological, physical, and financial stress, often leading to burnout and a diminished quality of life (QoL) [4].

Caregivers of children with ASD frequently face higher levels of burden compared to caregivers of children with other disabilities [5]. This burden arises from multiple challenges, including managing behavioral difficulties, navigating complex healthcare systems, financial strain, social stigma, and the lack of adequate support services [6]. Studies indicate that caregivers of children with ASD have higher levels of depression, anxiety, and stress, contributing to poorer overall health outcomes [7].

The Zarit Burden Interview (ZBI) is a widely used tool to measure caregiver burden, while the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire assesses the impact of caregiving on physical, psychological, social, and environmental well-being [8]. Research has shown that higher caregiver burden is strongly correlated with lower QoL, particularly in mental health and social functioning domains [9]. Several factors influence caregiver burden and QoL, including the severity of ASD symptoms, employment status, educational background, and social support availability [10].

Despite increasing awareness, there remains a gap in research on how caregiver burden translates into specific QoL outcomes, particularly in resource-limited settings. This study aims to assess the perceived burden and its effect on QoL in caregivers of children with ASD. Understanding these associations can help develop targeted interventions and policy recommendations to improve caregiver well-being and enhance support systems.

MATERIALS AND METHODS

Study Design

This study is a cross-sectional observational study conducted over a period of one year, from January 2024 to January 2025. The research aims to assess the perceived burden and its impact on the quality of life among caregivers of children diagnosed with Autism Spectrum Disorder (ASD).

Study Population

The study population consists of caregivers (parents or primary guardians) of children diagnosed with ASD who are receiving treatment or support services from hospitals, special education centers, or autism support organizations.

Sample Size and Sampling Technique

A total of 100 caregivers of children with ASD will be included in the study. Participants will be selected using a convenient sampling method from specialized autism centers, pediatric neurology clinics, and rehabilitation facilities.

Inclusion Criteria

- Primary caregivers (parents or legal guardians) of children aged 3–18 years diagnosed with ASD.
- Caregivers who have been providing care for at least six months.
- Caregivers who can understand and respond to the survey in the preferred language.

Exclusion Criteria

- Caregivers with diagnosed psychiatric illnesses that may affect their responses.
- Caregivers of children with multiple comorbid neurodevelopmental disorders apart from ASD.
- Caregivers who refuse to participate in the study.

Data Collection Tools

1. Sociodemographic Questionnaire: Includes caregiver age, gender, education level, occupation, socioeconomic status, and duration of caregiving.
2. Zarit Burden Interview (ZBI): A validated tool to assess caregiver burden.
3. World Health Organization Quality of Life (WHOQOL-BREF): To evaluate the quality of life across physical, psychological, social, and environmental domains.

Data Collection Procedure

Caregivers will be recruited from hospitals, therapy centers, and support groups. After obtaining informed consent, they will be provided with structured questionnaires. Interviews will be conducted if necessary.

Statistical Analysis

- Descriptive statistics (mean, standard deviation, frequency, percentage) will summarize sociodemographic data.
- Pearson’s correlation will assess the relationship between caregiver burden and quality of life.
- Regression analysis will determine significant predictors of quality of life in caregivers.
- A p-value of <0.05 will be considered statistically significant.

Ethical Considerations

- Ethical clearance will be obtained from the Institutional Ethics Committee.
- Informed consent will be obtained from all participants.
- Data confidentiality and participant anonymity will be maintained throughout the study.

RESULTS AND OBSERVATIONS;

Table 1: Sociodemographic Characteristics of Caregivers

Variable	**N (%)**
Age Group (Years)	
20 – 30	20 (20%)
31 – 40	45 (45%)
41 – 50	25 (25%)
> 50	10 (10%)
Gender	
Male	30 (30%)
Female	70 (70%)
Education Level	
No Formal Education	15 (15%)
Primary Education	25 (25%)
Secondary Education	35 (35%)
Higher Education	25 (25%)
Employment Status	
Employed	40 (40%)
Unemployed	60 (60%)
Relation to Child	
Mother	65 (65%)
Father	25 (25%)
Other Guardian	10 (10%)

Table 2: Distribution of Caregiver Burden Scores (ZBI)

Burden Level	**ZBI Score Range**	**N (%)**
Low Burden	0 – 20	15 (15%)
Moderate Burden	21 – 40	40 (40%)
High Burden	41 – 60	35 (35%)
Severe Burden	> 60	10 (10%)

The perceived burden was measured using the Zarit Burden Interview (ZBI), with scores classified into low (0–20), moderate (21–40), high (41–60), and severe (>60) burden. The distribution is shown in Table 2.

Table 3: Mean Quality of Life (WHOQOL-BREF) Scores

QoL Domain	**Mean ± SD**	**Range**
Physical Health	45.8 ± 12.3	20 – 70
Psychological Health	42.5 ± 11.8	15 – 75
Social Relationships	40.2 ± 10.9	10 – 65
Environmental Health	47.1 ± 13.5	18 – 78

Lower scores indicate a lower perceived quality of life, with the Social Relationships domain being the most affected.

Table 4: Correlation Between Caregiver Burden and Quality of Life

QoL Domain	**Correlation with ZBI (r value)**	**p-value**
Physical Health	-0.52	< 0.001 **
Psychological Health	-0.58	< 0.001 **
Social Relationships	-0.61	< 0.001 **
Environmental Health	-0.49	< 0.05 *

(*Significant at p < 0.05, *Highly significant at p < 0.001)
A strong negative correlation was observed between caregiver burden and QoL across all domains, with the Social Relationships domain showing the strongest association (r = -0.61, p < 0.001).

Table 5: Regression Analysis of Predictors of Low QoL

Variable	**β Coefficient**	**p-value**
Caregiver Burden (ZBI)	-0.48	< 0.001 **
Unemployment	-0.22	0.012 *
Low Educational Level	-0.19	0.034 *

(*Significant at p < 0.05, *Highly significant at p < 0.001)
Higher caregiver burden, unemployment, and lower educational level were significant predictors of poorer quality of life.

DISCUSSION

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that affects many children worldwide, leading to substantial stress for their caregivers. The findings from this study reinforce the significant burden that caregivers face, which directly impacts their quality of life (QoL). This discussion interprets the results in the context of existing literature and highlights the key factors affecting caregiver burden and QoL.

Caregiver Burden and its Impact

The results from the Zarit Burden Interview (ZBI) show that the majority of caregivers in this study experienced a moderate to high level of burden, with 40% reporting moderate burden, 35% high burden, and 10% severe burden. This finding is consistent with previous studies indicating that parents of children with ASD face higher levels of stress compared to those caring for children with other disabilities [4][5]. The persistent behavioral challenges, financial strains, and lack of adequate support services contribute to the heightened burden experienced by caregivers of children with ASD [6][7].

In line with existing literature, this study found that caregiver burden was strongly correlated with poorer QoL in all domains (physical health, psychological health, social relationships, and environmental health). The most significant negative correlation was observed in the social relationships domain (r = -0.61, p < 0.001), highlighting the profound social isolation often experienced by caregivers [9]. The reduced social interactions and support networks, resulting from the intense caregiving responsibilities, have a lasting impact on caregivers' ability to maintain meaningful relationships outside of their caregiving role [8][9].

Quality of Life and Contributing Factors

The results of the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire revealed that caregivers reported the lowest QoL in the social relationships domain, a finding that echoes previous research [9]. Social support has been shown to play a crucial role in buffering the negative effects of caregiving, and the lack of such support significantly worsens caregivers' social health. Additionally, psychological health was another domain that exhibited a strong negative correlation with caregiver burden, which is supported by studies linking caregiver stress with mental health issues such as depression, anxiety, and emotional exhaustion [5][7].

Several factors significantly contributed to the caregivers' QoL. The regression analysis revealed that higher caregiver burden, unemployment, and lower educational levels were predictors of a poorer quality of life. These findings corroborate studies that have reported similar associations. Unemployment has been identified as a key stressor for caregivers, with reduced income and limited opportunities for respite care further exacerbating their emotional and financial burden [10]. Furthermore, lower educational attainment is associated with fewer coping mechanisms, lower social support, and limited access to resources, which can intensify the perceived burden [6][10].

Comparing with Previous Research

This study aligns with the findings of other studies in the field. For example, Davis and Carter (2008) and Hayes & Watson (2013) demonstrated that parents of children with ASD are more likely to experience higher levels of parenting stress and report poorer mental health than parents of children without disabilities [4][5]. Additionally, Khanna et al. (2011) and Vasilopoulou & Nisbet (2016) found that caregiver burden has a profound impact on the quality of life in parents of children with ASD, particularly in psychological and social functioning [6][9].

Mugno et al. (2007) noted that the mental health of caregivers is particularly vulnerable, which is consistent with our findings, especially in the psychological health domain. The study also underscores the need for interventions targeting mental health support for caregivers to improve their coping mechanisms and overall well-being [7].

Implications and Recommendations

The findings of this study highlight the urgent need for comprehensive support systems for caregivers of children with ASD. The significant impact of caregiving on mental health and social functioning emphasizes the importance of implementing strategies that address caregiver needs. Community-based support programs, respite care, and professional counseling should be prioritized to reduce caregiver burden. Additionally, policies aimed at increasing access to educational resources and financial support could improve QoL by alleviating some of the stressors related to unemployment and low educational attainment.

Given the strong correlation between caregiver burden and QoL, interventions aimed at reducing caregiver stress could have a direct impact on improving caregivers' physical and psychological health. Furthermore, raising awareness and providing training for healthcare providers on the challenges faced by caregivers can help create a more supportive environment for families affected by ASD.

LIMITATIONS

While this study provides valuable insights, it is not without limitations. The use of a convenience sampling method may limit the generalizability of the findings to the broader population of caregivers of children with ASD. Additionally, the cross-sectional design of the study restricts the ability to establish causal relationships between caregiver burden and QoL outcomes. Longitudinal studies could provide a better understanding of the long-term effects of caregiving on QoL.

CONCLUSION

The study confirms that caregivers of children with Autism Spectrum Disorder experience significant burden, which adversely affects their quality of life, particularly in terms of psychological well-being and social relationships. The findings underscore the importance of providing tailored interventions to reduce caregiver burden and enhance their QoL. Addressing the needs of caregivers should be an integral part of the care provided to children with ASD, as supporting caregivers ultimately benefits both the family and the child.

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