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Psychological Determinants and Caregiving Factors Influencing Burden, Burnout, Subjective well-being among Parents of Children with Neurodevelopmental Disorders in Rural India: A Cross-Sectional Analytical Study

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Abstract

Background: *The Parents of children with neurodevelopmental disorders (NDDs) experience substantial psychological and caregiving challenges. These difficulties may be amplified in rural settings because of limited access to mental health services, rehabilitation services, healthcare, and social support. This study examined the relationships of psychological distress, caregiver burden, social support, burnout, and subjective wellbeing among parents of children with neurodevelopmental disorders in rural India.* ***Method:*** *Study was conducted a cross-sectional analytical design, among 250 parents or primary caregivers of children aged 2–18 years diagnosed with neurodevelopmental disorders, including autism spectrum disorder, attention-deficit/hyperactivity disorder, intellectual disability, and global developmental delay. All the Participants were recruited by using purposive sampling technique from child rehabilitation clinics, tertiary care hospitals, and developmental assessment units in rural Karnataka. To assess perceived stress, depression, anxiety, caregiver burden, perceived social support, and caregiver burnout the Standardized tools were used and data were analyzed by using descriptive statistics, Pearson correlation, multiple linear regression, and structural equation modeling (SEM).* ***Results:*** *The mean caregiver age was 34.8 years (SD = 6.2), and 72% were female caregivers. The High perceived stress was reported by 68% of caregivers and was positively associated with depression (r = .59), depressive symptoms by 52%, moderate-to-high anxiety by 49%, and high caregiver burden by 61%. Caregiver burden (r = .62), and burnout (r = .56), ps < .001. The Social support was significantly associated with lower stress, depression, caregiver burden, and burnout, and with better quality of life (ps < .001).Caregiver burden (β = .41), depression (β = .35), and stress (β = .28) significantly predicted adverse caregiver outcomes. The SEM demonstrated acceptable fit (CFI = .93, RMSEA = .05, χ^2/df = 2.10).* ***Conclusion:*** *The Caregivers of children with neurodevelopmental disorders experience considerable psychological distress and caregiving burden in rural India, and culturally appropriate community-based interventions are strengthening social support, resilience; improve caregiver well-being and quality of life.*

Keywords

Burnout, caregiver, neurodevelopmental disorders, quality of life, rural India, social support.

INTRODUCTION

The Neurodevelopmental disorders (NDDs) are comprise a group of developmental conditions characterized by impairments in cognitive, communicative, behavioral, and adaptive functioning, with onset during the developmental period. The Neurodevelopmental disorders (NDDs); autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), and intellectual disability (ID), conditions may persist throughout the lifespan and often require continuous supervision, therapeutic intervention, educational support, and family involvement. Consequently, parents and other family caregivers may experience emotional, physical, social, and financial demands associated with long-term caregiving. Evidence from different clinical populations indicates that parents of children with developmental and neurodevelopmental conditions experience significantly greater parenting stress than parents of typically developing children [1], [2]. The burden of neurodevelopmental disorders In India is substantial. Highlighting the need for early identification and appropriate intervention services are population-based evidence from multiple regions of the country has demonstrated a considerable prevalence of developmental difficulties among children [3]. Despite this substantial burden in rural and underserved communities, recognition and diagnosis of NDDs remain challenging due to limited awareness, social stigma, inadequate screening facilities, shortages of trained professionals, and restricted access to specialized healthcare services may contribute to delayed identification and intervention. These challenges can place additional psychological and caregiving demands on families.

The children with neurodevelopmental disorder parents are experienced elevated levels of psychological distress,

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including stress, anxiety, depressive symptoms, and reduced quality of life due to underrecognized component of comprehensive child care and the psychological well-being of parents is an important. The previous studies have reported the children with ASD and other neurodevelopmental disorders parents are considerable impaired quality of life and psychological [4], [5]. The caregiving burden may arise not only from the child's functional limitations but also from the continuous nature of supervision, behavioral management, treatment requirements, educational concerns, and uncertainty regarding the child's long-term development and independence. A substantial body of research has consistently shown that parents of children with neurodevelopmental disorders, particularly autism spectrum disorder and developmental disabilities, significantly experience higher levels of parental stress compared to parents of typically developing children [1], [2], therefore, it is important to understanding parenting stress in particularly in caregiver outcomes. The intensity and perceived stress influenced by the child's behavioral characteristics, developmental difficulties, functional dependence, and care requirements. In addition, parental perceptions, coping resources, and availability of social and professional support may determine how caregiving demands are experienced and managed.

The child's daily care, in Indian caregiving context is predominantly family-centered, and the parents are primary responsibility for the child's daily care, treatment coordination, education, and rehabilitation. Families living in rural areas may experience additional challenges, due to inadequate mental-health resources, geographical barriers to specialized services, limited healthcare infrastructure, lower health literacy, financial constraints, and reduced access to formal support systems [6], [7]. These contextual disadvantages may increase psychological vulnerability among caregivers and it may further compromise their quality of life. Community-based mental-health and family-support interventions are important components of mental-health service development in resource-constrained settings [8].

The several interrelated psychological and social factors may directly contribute for caregiver burden and psychological distress. Similarly, perceived social support from family members, friends, healthcare professionals, and community networks may reduce psychological distress and improve caregiver's ability to cope with caregiving responsibilities. The recent Evidence suggests that stronger social support is generally associated with better mental-health outcomes among caregivers [9]. However, stigma, social isolation, and limited community awareness may restrict access to meaningful social support, particularly in rural settings. The multidimensional Caregiver burden is including emotional, physical, social, and financial components. The Reliable Psychological assessment of caregiver burden is identifying caregivers are requiring psychological and social interventions, the Multidimensional approaches to caregiver burden have demonstrated the importance of examining different domains of caregiving experiences rather than treating burden as a single construct [10]. The use of validated and psychometrically robust measures of perceived stress, social support, and psychological distress is essential for systematically and reliably assessing the psychological factors that influence caregiver well-being, coping capacity, and overall caregiving outcomes. [9], [11], [12].

The important contributor to caregiver burden and quality of life is Child-related characteristics represent, Greater symptom severity, behavioral difficulties, functional dependence, and increased caregiving responsibilities are creating higher caregiver burden and poorer quality of life [13]. Recent evidenced Indian existing many studies similarly indicates have primarily examined individual variables or relied on simple descriptive and bivariate analyses, providing limited understanding of the complex relationships among psychological and caregiving factors are considerable levels of caregiver burden, psychological distress, and depressive symptoms among parents and caregivers of children with developmental disabilities.

To understanding how stress, coping, social support, and caregiver burden interact within the specific sociocultural and socioeconomic context of rural India. Therefore Examining these important variables simultaneously through multivariate analytical approaches may provide a more comprehensive understanding of the factors associated with caregiver well-being. Such this approach is particularly relevant in rural communities, where healthcare accessibility, socioeconomic limitations, social stigma, and availability of professional support may substantially influence caregiving experiences.

Therefore, the present study aims to examine the multivariate relationships among perceived stress, coping, resilience, social support, caregiver burden, and quality of life among parents of children with neurodevelopmental disorders in rural India. Understanding these interrelationships may help identify modifiable psychological and social factors provide and developing culturally appropriate, evidence base psychological interventions for family-centered and caregivers of children with Neurodevelopmental disorders.

Objectives

1. To assess the levels of psychological distress among parents of children with neurodevelopmental disorders.
2. To assess the levels of caregiver burden and burnout among parents of children with neurodevelopmental disorders
3. To examine the relationships between psychological factors (stress, depression, anxiety, caregiver burden, social support) and caregiver outcomes.
4. To determine the predictive role of caregiver burden, psychological distress, and social support on caregiver quality of life and burnout.

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5. To evaluate the direct and indirect pathways between psychological factors and caregiver outcomes using structural equation modeling (SEM).

MATERIALS AND METHODS

Study Design

The Cross-sectional Analytical Study design was employed to examine the association between psychological factors and caregiver outcomes among parents of children with neurodevelopmental disorders. This design enabled assessment of multiple psychological variables at a single time point and facilitated evaluation of predictive relationships using multivariate statistical approaches.

Study Setting

The study was conducted in selected child rehabilitation clinics, tertiary care hospitals, and developmental assessment units providing services for children with neurodevelopmental disorders in rural Karnataka, India.

Study Population

The study population consisted of parents or primary caregivers of children diagnosed with neurodevelopmental disorders.

Sample Size

The sample size was estimated using Cochran's formula by using prevalence studies. Assuming a 95% confidence level (Z = 1.96), an expected prevalence of 50% to account for maximum variability, and an absolute precision of 6%, the estimated minimum sample size was approximately **267 participants**. The formula used was ($n = Z^2 P(1-P)/d^2$), where ***n*** represents the required sample size, ***Z*** is the standard normal deviate corresponding to the desired confidence level, ***P*** is the expected prevalence, and ***d*** is the desired precision [14].

Considering the feasibility of recruitment, availability of eligible participants, statistical power, and the planned multivariate analyses, including structural equation modeling (SEM), the final sample size was fixed at **250 participants**. Previous methodological recommendations indicated that sample sizes of approximately 200–250 participants are generally adequate for stable parameter estimation in SEM and complex multivariate models [15], [16], [17].

Sampling Technique

A **purposive sampling technique** was used to recruit participants who fulfilled the eligibility criteria.

Eligibility Criteria

Inclusion Criteria

Participants were included if they:

1. The parents or primary caregivers of children diagnosed with a neurodevelopmental disorder.
2. The children aged between **2 and 18 years.**
3. Directly involved in the child's day-to-day caregiving and management.
4. Provided written informed consent.
5. To able to understand and complete the study questionnaires.

Exclusion Criteria

Participants were excluded if they:

1. Diagnosed with severe psychiatric disorder and requiring active treatment.
2. Non-primary caregivers.
3. Returned incomplete questionnaires.
4. Unable to provide reliable responses due to communication difficulties.

Measurement Tools

Standardized and validated psychological instruments were used to assess psychological factors and caregiver outcomes.

Perceived Stress

The Perceived Stress is measured by using 10-items self-report Perceived Stress Scale (PSS-10. It has demonstrated good internal consistency (Cronbach's $\alpha = .84–.86$) and acceptable test–retest reliability. Evidence of construct and criterion-related validity has been established across different populations [18].

Depression

The depression is measured by using 21-items self-report Beck Depression Inventory-II (BDI-II). Beck Depression Inventory-II is an instrument designed to assess the severity of depressive symptoms. It demonstrates excellent internal consistency (Cronbach's $\alpha \approx .92$) and high test–retest reliability ($r \approx .93$). The Beck Depression Inventory-II is established convergent, discriminant, and constructs validity in clinical and community populations [19].

Anxiety

The anxiety is measured by using Generalized Anxiety Disorder-7 (GAD-7) scale. This scale has demonstrated good criterion, construct, and factorial validity, with strong sensitivity and excellent internal consistency (Cronbach's $\alpha = .92$) and good test–retest reliability (ICC = .83). GAD-7 is a 7-item screening scale assessing symptoms of generalized anxiety [20].

Caregiver Burden

The caregiver burden is assessed by using 22-items Zarit Burden Interview (ZBI). ZBI is an instrument assessing subjective caregiver burden associated with emotional, physical, social, and financial challenges of caregiving. The scale ZBI demonstrated high internal consistency (Cronbach's α generally $> .90$) and good test–retest reliability evidence supports its construct and concurrent validity for assessing caregiver burden [21].

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Perceived Social Support

The 12-items Multidimensional Scale of Perceived Social Support (MSPSS) demonstrates good factorial and construct validity across different populations with good internal consistency (Cronbach's α = .88) and test–retest reliability (ICC = .85). The MSPSS is using for assessing perceived social support from family, friends, and significant others [22], [23].

Caregiver Burnout Inventory (CBI)

The Caregiver Burnout Inventory (CBI) consists of 24 items assessing five dimensions: time-dependence, developmental, physical, social, and emotional burden. The CBI demonstrates high internal consistency (Cronbach's α ≈ .93) and evidence of content and construct validity supporting its multidimensional structure. Higher scores indicate greater caregiver burnout [24].

Data Collection Procedure

Data collection was initiated after eligible caregivers were identified during routine clinical visits and written informed consent and ascent was obtained before test administered. The purpose of the study, procedures involved, potential benefits, voluntary nature of participation, and measures adopted to maintain confidentiality were explained to participants in their preferred language and Potential participants were approached and invited to participate in the study.

Statistical Analysis

The Data were analyzed using the descriptive and inferential statistical methods. To summarize participant characteristics and psychological variables used Frequency, percentage, mean, and standard deviation methods. The Correlation, multiple linear regression, and structural equation modeling (SEM) methods were used for study Relationships and predictive pathways. Comparative Fit Index (CFI), Root Mean Square Error of Approximation (RMSEA), and chi-square/degrees of freedom ratio (χ^2/df) using for evaluated structural equation modeling (SEM) model fit. A p-value < .05 was considered statistically significant.

RESULTS

Table 1. Levels of Psychological Distress and Caregiver Burden among Parents of Children with Neurodevelopmental Disorders (N = 250)

Psychological distress	Level	n	%
Perceived stress	High perceived stress	170	68.0
Depressive symptoms	Clinically significant depressive symptoms	130	52.0
Anxiety symptoms	Moderate-to-high anxiety	123	49.0

The findings in table 1 shows that perceived stress is most frequently observed psychological challenge (68.0%), depressive symptoms are showing clinically significant (52.0%) and anxiety symptoms are showing moderate to high (49.0%). It indicates that psychological distress is common among parents of children with neurodevelopmental disorders.

Table 2. Levels of Caregiver Burden and Burnout among Parents (N = 250)

Caregiver outcome	Level	n
Caregiver burden	High	153
Burnout	High	172

The findings in the table 2 revealed High caregiver burden was reported by 61.0% (n = 153) of participants, and 68.8% (n = 172) experienced high levels of burnout.

Table 2A. Association between Caregiver Burden and Burnout

Variables	r	p-value
Caregiver burden – Burnout	.63	< .001

Table 2A indicates that the strong positive correlation between caregiver burden and burnout (**r = .63, p < .001**) suggests that caregiving challenges may represent a major contributor to caregiver exhaustion and reduced psychological functioning.

Table 3. Pearson Correlation Matrix of Psychological Factors and Caregiver Outcomes

Variable	Stress	Depression	Caregiver burden	Social support	Burnout	QOL
Stress	1	.59***	.62***	−.48***	.56***	−.52***
Depression	—	1	.58***	−.41***	.60***	−.61***
Caregiver burden	—	—	1	−.39***	.63***	−.55***
Social support	—	—	—	1	−.47***	.49***
Burnout	—	—	—	—	1	—
Quality of life	—	—	—	—	—	1

***p < .001.

Table 3, revealed that psychological factors of Perceived stress was positively associated with caregiver burden (r = .62, p < .001), burnout (r = .56, p < .001), and depression (r = .59, p < .001). And showing negative associations with social

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support (r = −.48, p < .001) and quality of life (r = −.52, p < .001). The psychological factor Depression was positively associated with caregiver burden (r = .58, p < .001) and burnout (r = .60, p < .001), but negatively associated with quality of life (r = −.61, p < .001). Caregiver burden demonstrated the strongest association with burnout (r = .63, p < .001) and was negatively associated with quality of life (r = −.55, p < .001). In contrast, social support was negatively associated with psychological factors like, stress (r = −.48), depression (r = −.41), care giving factors like caregiver burden (r = −.39), and burnout (r = −.47), and positively associated with quality of life (r = .49), with all correlations statistically significant at p < .001.

Table 4. Multiple Linear Regression Analysis of Caregiver Outcomes

Predictor	Standardized β	SE	t	p
Caregiver burden	.41	.05	8.20	< .001
Depression	.35	.04	7.45	< .001
Perceived stress	.28	.06	5.60	< .01
Social support	−.29	.05	−5.80	< .01
Model R^2	**.58**			

The table 4 Multiple linear regression analysis demonstrated that predictors of caregiver outcomes are collectively explaining 58% of the variance (R^2 = .58). Caregiver burden of caregiver factors emerged as the strongest positive predictor (β = .41, p < .001), followed by depression (β = .35, p < .001) and perceived stress (β = .28, p < .01). In contrast, social support showed a significant negative association (β = −.29, p < .01), indicating a potential protective effect.

Table 5. Structural Equation Model Fit Indices

Fit index	Obtained value	Recommended criterion	Interpretation
CFI	0.93	≥ 0.90	Acceptable fit
RMSEA	0.05	≤ 0.08	Good fit
χ^2/df	2.10	< 3.00	Acceptable fit

Table 5 the structural equation model demonstrated that the CFI value of **0.93** indicated that the proposed model adequately reproduced the observed relationships, and the RMSEA of **0.05** indicated a close model fit. The χ^2/df ratio of **2.10** was within the accepted range, collectively supporting the **adequacy of the proposed structural model.**

Table 6. Structural Equation Model (SEM) Direct Path Coefficients

Direct pathway	Standardized β	p-value	Interpretation
Perceived stress → Burnout	.52	< .001	Significant positive pathway
Caregiver burden → Depression	.48	< .001	Significant positive pathway
Depression → Quality of life	−.55	< .001	Significant negative pathway
Social support → Resilience	.51	< .001	Significant protective pathway

Table 6 in the SEM indicates Perceived stress significantly predicted burnout (**β = .52, p < .001**), and caregiver burden significantly predicted depression (**β = .48, p < .001**). Psychological factor Depression was significantly associated with poorer quality of life (**β = −.55, p < .001**), which highlighting the adverse impact of psychological distress on caregiver well-being. In contrast, social support demonstrated a significant positive association with resilience (**β = .51, p < .001**), Structural Equation Model (SEM) revealed significant direct pathways linking psychological distress, caregiver burden, and caregiver outcomes.

DISCUSSION

The present study demonstrates a substantial and interconnected burden of psychological distress and caregiving difficulties among parents of children with neurodevelopmental disorders (NDDs). The psychological factor Perceived stress was the most frequently observed psychological problem (68.0%), followed by clinically significant depressive symptoms (52.0%) and moderate-to-high anxiety symptoms (49.0%). The recent Indian studies similarly demonstrates high levels of stress, anxiety, depression, caregiver burden, and impaired quality of life among parents of children with developmental and special healthcare needs [25], [26], [27]. These India study findings indicate that psychological morbidity is common among parents managing the long-term developmental, behavioural, and functional needs of their children and the Caregiver burden was high in 61.0% of participants, while 68.8% experienced high burnout, emphasizing the cumulative challenges of prolonged caregiving. The strong positive correlation between caregiver burden and burnout (r = .63, p < .001). The Indian literature describing caregiving as a lifelong process suggests that sustained caregiving challenges may contribute substantially to emotional, social, practical and psychological challenges. [28], [29]. The correlation findings stress was associated with caregiver burden (r = .62) and burnout (r = .56), while depression demonstrated a strong negative association with quality of life (r = −.61). In particular, findings support previous evidence that social support can reduce parenting stress and improve quality of life among parents of children with developmental disabilities [30], [31], [32]. The further demonstrate an interconnected pattern social support and quality of life showed predominantly protective associations, the perceived stress, depression, caregiver burden, and burnout were significantly related positively.

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Regression analysis identified caregiver burden (β = .41), depression (β = .35), perceived stress (β = .28), and social support (β = −.29) as significant predictors, collectively explaining 58% of the variance. The SEM findings strengthened this interpretation: perceived stress predicted burnout (β = .52), caregiver burden predicted depression (β = .48), and depression predicted poorer quality of life (β = −.55), whereas social support positively predicted resilience (β = .51). The satisfactory model fit (CFI = .93, RMSEA = .05, χ^2/df = 2.10) supports the proposed interrelationships. Indian intervention evidence also suggests that parent-to-parent support can reduce parental stress and anxiety, highlighting the importance of caregiver-focused psychosocial interventions [33].

Overall, the study findings emphasize that caregiver well-being should be integrated into routine services for children with NDDs, rather than focusing exclusively on the child's needs. The routine psychological screening for stress, depression, anxiety, caregiver burden, and burnout, along with psychoeducation, peer-support groups, resilience-building interventions, and family-centred services, enhance parental psychological well-being and, ultimately, strengthen the quality of life and continuity of care provided to children with Neurodevelopmental disorders [34], [35], [36].

CONCLUSION

The present study demonstrates a substantial and interconnected burden of psychological distress factors, perceived stress, depression, and anxiety the caregivers factors of caregiver burden, burnout, and impaired quality of life among parents of children with neurodevelopmental disorders. High stress and burnout were particularly prominent, and caregiver burden emerging as the strongest predictor of adverse caregiver outcomes. The Social support showed as a consistent protective pattern and positively associated with quality of life and resilience. The SEM identified significant pathways linking stress with burnout, caregiver burden with depression, and depression with poorer quality of life. These findings support integrating routine mental-health screening, caregiver-focused interventions, peer support, and family-centred rehabilitation services into NDD care in India.

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