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Caregiver Burden among parents of children with Autism Spectrum Disorder and Cerebral Palsy: The role of socioeconomic status

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Abstract

Caregiving for children with neurodevelopmental disabilities places substantial psychological, physical, and financial demands on families, often resulting in heightened caregiver burden. The present study examines the influence of socioeconomic status (SES) on caregiver burden among parents of children diagnosed with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP), two conditions characterized by chronic care needs but differing in behavioural and physical dependency profiles. Using a comparative cross-sectional design, the study assessed 50 primary caregivers (25 parents of children with ASD and 25 parents of children with CP) recruited from special schools and therapy centres in Varanasi, India. Socioeconomic status was measured using the Kuppuswamy Socioeconomic Status Scale, while caregiver burden was assessed through the Burden Assessment Schedule developed by the Schizophrenia Research Foundation (SCARF), India.

Findings revealed a statistically significant difference in caregiver burden between the two groups, with parents of children with ASD reporting higher levels of burden than parents of children with CP. Additionally, socioeconomic status emerged as a strong predictor of caregiver burden, with caregivers from lower SES backgrounds experiencing significantly greater burden compared to those from middle and higher SES groups. The results highlight the compounding effects of financial strain, limited access to healthcare services, and inadequate social support on caregiver well-being. Behavioural challenges, long-term rehabilitation needs, and uncertainty regarding the child's future further intensified caregiver stress.

The study underscores the critical need for SES-sensitive intervention models, enhanced psychosocial support, and inclusive public health policies aimed at reducing caregiver burden. Early identification of caregiver stress and targeted support for economically disadvantaged families may play a vital role in improving both caregiver well-being and child outcomes.

Keywords: Caregiver burden, socioeconomic status, autism spectrum disorder, cerebral palsy, parents

Introduction

Caregiver Burden in Childhood Neurodevelopmental Disabilities

Caring for a child with a neurodevelopmental disability constitutes a long-term commitment that profoundly affects family systems, parental well-being, and socioeconomic stability. Neurodevelopmental disabilities such as Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP) are chronic, lifelong conditions that often require continuous medical care, behavioral intervention, rehabilitation, and educational support. The cumulative demands of caregiving frequently give rise to what is conceptualized as *caregiver burden*, a multidimensional construct encompassing emotional distress, physical exhaustion, social restriction, and financial strain (Zarit *et al*., 1980; Raina *et al*., 2005) [2, 30].

Extensive research has demonstrated that parents of children with developmental disabilities experience significantly higher levels of stress, anxiety, and depressive symptoms compared to parents of typically developing children (Brehaut *et al*., 2004; Emerson & Hatton, 2007) [5, 10]. Chronic exposure to caregiving stress has been associated with adverse health outcomes among caregivers, including sleep disturbances, musculoskeletal pain, compromised immune functioning, and reduced quality of life (Pinquart, 2018) [24]. Consequently, caregiver burden is increasingly recognized as a major public health concern that warrants systematic investigation, particularly in resource-limited settings.

Autism Spectrum Disorder and Parental Caregiving Challenges

Autism Spectrum Disorder is a neurodevelopmental condition characterized by persistent deficits in social communication and social interaction, along with restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013) [1]. The heterogeneity of ASD, combined with its early onset and uncertain developmental trajectory, presents unique challenges for caregivers. Parents of children with ASD frequently report high levels of emotional stress related to behavioural difficulties, communication impairments, sensory sensitivities, and co-occurring conditions such as attention-deficit/hyperactivity disorder, anxiety, and sleep disorders (Karst & Van Hecke, 2012; Hayes & Watson, 2013) [14, 17].

Behavioural management demands are a significant contributor to caregiver burden in ASD. Externalizing behaviors, emotional dysregulation, and social impairments often require constant supervision and specialized intervention, leading to heightened parental vigilance and emotional fatigue (Estes *et al*., 2013) [11]. Moreover, societal misunderstanding and stigma associated with autism frequently result in social isolation, reduced community participation, and limited informal support for families (Gray, 2002) [12]. Studies consistently indicate that caregivers of children with ASD experience greater psychological burden compared to caregivers of children with other developmental disabilities (Pisula & Porębowicz-Dörsmann, 2017) [25].

Cerebral Palsy and Physical Demands of Caregiving

Cerebral Palsy is primarily a disorder of movement and posture caused by non-progressive disturbances in the developing fatal or infant brain (Rosenbaum *et al*., 2007) [27]. Although cognitive and sensory impairments may co-occur, the hallmark of CP is motor dysfunction, which often necessitates substantial physical caregiving. Parents of children with CP are commonly responsible for assisting with mobility, feeding, toileting, positioning, and therapeutic exercises, resulting in sustained physical exertion (Novak *et al*., 2012) [21].

The physical demands associated with caregiving for children with CP place caregivers at increased risk for musculoskeletal injuries, chronic pain, and fatigue (Tong *et al*., 2020) [28]. In addition to physical strain, caregivers often experience emotional distress related to concerns about functional limitations, accessibility barriers, and long-term dependency of the child (Khan *et al*., 2022) [18]. While behavioral challenges may be less prominent than in ASD, the intensive nature of physical care contributes significantly to caregiver burden and impacts overall family functioning.

Socioeconomic Status as a Determinant of Caregiver Burden

Socioeconomic status (SES) is a critical contextual factor influencing caregiver burden across disability populations. SES, typically operationalized through indicators such as income, education, and occupation, shapes caregivers' access to healthcare services, rehabilitation resources, assistive devices, and social support networks (Bradley & Corwyn, 2002) [4]. Caregivers from lower socioeconomic backgrounds often face compounded stressors, including financial insecurity, limited access to specialized care, and reduced capacity to absorb indirect caregiving costs such as lost employment opportunities (Emerson, 2003) [9].

Empirical evidence consistently demonstrates an inverse relationship between SES and caregiver burden, with caregivers from lower SES groups reporting higher levels of stress, depression, and perceived overload (Desai *et al*., 2019; Park *et al*., 2020) [8, 22]. Financial strain associated with treatment costs, transportation, and long-term rehabilitation frequently exacerbates caregiver distress, particularly in families without stable income or health insurance coverage. SES not only affects material resources but also influences psychological resilience and coping strategies, thereby shaping caregiving experiences.

Caregiver Burden in the Indian Context

In low- and middle-income countries such as India, the relationship between SES and caregiver burden is further intensified by structural and systemic challenges. Limited public health infrastructure, scarcity of specialized rehabilitation services, high out-of-pocket healthcare expenditures, and inadequate disability-inclusive policies place a disproportionate burden on families (Kumar *et al*., 2019) [19]. Cultural beliefs and stigma surrounding disability often discourage help-seeking behaviors and contribute to social exclusion of both children with disabilities and their caregivers (Gupta & Singhal, 2004) [13].

Caregiving responsibilities in India are predominantly assumed by mothers, leading to gendered patterns of burden and psychological distress. Women caregivers frequently report disruptions in employment, reduced social participation, and heightened emotional strain (Baker & Drapela, 2010) [2]. Rural and semi-urban populations face additional barriers due to geographical isolation and lack of awareness regarding evidence-based interventions, further amplifying caregiver burden.

Need for Comparative and SES-Sensitive Research

Despite growing global literature on caregiver burden, comparative studies examining differences between caregivers of children with ASD and CP remain limited, particularly within the Indian context. Existing research often focuses on single diagnostic categories or fails to adequately account for the moderating role of socioeconomic status (Benson, 2014) [3]. Understanding how disability type interacts with SES to influence caregiver burden is essential for developing targeted, culturally responsive, and economically feasible interventions.

Objectives

1. To examine the impact of socioeconomic status on caregiver burden among parents of children with Autism Spectrum Disorder and Cerebral Palsy.
2. To compare the level of caregiver burden between parents of children with ASD and CP.

Hypotheses

H1: Socioeconomic status will be significantly associated with caregiver burden among parents of children with ASD and CP, with lower SES associated with higher burden.

H2: There will be a significant difference in caregiver burden between parents of children with ASD and parents of children with CP.

Methodology

Research Design

A comparative cross-sectional research design was employed.

Sample

The sample comprised 50 primary caregivers (25 ASD, 25 CP) recruited from therapy centers and special schools in Varanasi, Uttar Pradesh, India. All participants belonged to low or middle socioeconomic status groups.

Tools

- Kuppuswamy Socioeconomic Status Scale
- Burden Assessment Schedule (SCARF, India)

Procedure

Data were collected through structured interviews after obtaining informed consent.

Statistical Analysis

Independent samples t test and one-way ANOVA were used. Statistical significance was set at $p < .05$.

Results

Table 1: Comparison of Caregiver Burden Between Parents of Children with ASD and CP

Group	N	Mean	SD	*t*
ASD	25	77.16	13.29	2.45
CP	25	68.36	12.07	

df = 48, p =.018

Interpretation

An independent-samples *t* test was conducted to examine differences in caregiver burden between parents of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP). The analysis revealed a statistically significant difference in caregiver burden between the two groups, *t* (48) = 2.45, *p* =.018 (see Table 1). Parents of children with ASD reported significantly higher levels of caregiver burden (*M* = 77.16, *SD* = 13.29) than parents of children with CP (*M* = 68.36, *SD* = 12.07). This finding indicates that caregivers of children with ASD experience greater overall burden compared to caregivers of children with CP.

Table 2: ANOVA Showing SES Differences in Caregiver Burden

SES Level	Mean	SD	*F*
High	53.25	4.95	22.19
Moderate	62.05	5.59	
Low	77.16	13.29	

p <.001

Interpretation of ANOVA

A one-way analysis of variance (ANOVA) was performed to examine differences in caregiver burden across socioeconomic status (SES) groups. Results indicated a statistically significant effect of SES on caregiver burden, *F* (2, 47) = 22.19, *p* <.001 (see Table 2). Caregivers belonging to the low SES group reported the highest levels of burden (*M* = 77.16, *SD* = 13.29), followed by caregivers from the moderate SES group (*M* = 62.05, *SD* = 5.59). Caregivers from the high SES group reported the lowest levels of burden (*M* = 53.25, *SD* = 4.95).

Table 3: Post-Hoc Comparisons of Caregiver Burden Across SES Groups

Comparison	Mean Difference	*p*
High vs Moderate	8.80	<.01
High vs Low	23.91	<.001
Moderate vs Low	15.11	<.001

Post-Hoc Comparisons Across SES Groups

Post-hoc comparisons were conducted to identify specific differences in caregiver burden among the SES groups (see Table 3). The results demonstrated that caregiver burden was significantly lower among high SES caregivers compared to moderate SES caregivers (*p* <.01) and low SES caregivers (*p* <.001). In addition, caregivers in the moderate SES group reported significantly lower burden than those in the low SES group (*p* <.001). These findings confirm that caregiver burden increases significantly as socioeconomic status decreases.

Discussion

The present study examined caregiver burden among parents of children with Autism Spectrum Disorder and Cerebral Palsy, with particular emphasis on the role of socioeconomic status. The findings provide important insights into how disability type and socioeconomic disadvantage jointly shape caregiving experiences in the Indian context. Overall, the results confirm that caregiver burden is significantly influenced by both socioeconomic status and the nature of the child's disability.

Differences in Caregiver Burden Between ASD and CP

The findings revealed a statistically significant difference in caregiver burden between parents of children with ASD and those of children with CP, with caregivers of children with ASD reporting higher overall burden. This result is consistent with previous research indicating that behavioural and emotional management demands associated with ASD contribute substantially to parental stress and psychological distress (Hayes & Watson, 2013; Pisula & Porębowicz-Dörsmann, 2017) [14, 25]. Unlike CP, where caregiving challenges are predominantly physical, ASD caregiving involves managing unpredictable behaviors, communication difficulties, and social impairments, which often require continuous emotional regulation and vigilance from parents.

Parents of children with ASD may also experience heightened uncertainty regarding prognosis, social acceptance, and future independence, which further amplifies emotional burden. These findings align with earlier studies reporting elevated levels of anxiety, depression, and emotional exhaustion among autism caregivers compared to caregivers of children with other developmental disabilities (Estes *et al*., 2013) [11]. In contrast, although caregiving for children with CP is physically demanding, the relative predictability of motor impairments and rehabilitation routines may reduce emotional ambiguity, thereby resulting in comparatively lower overall burden scores.

Impact of Socioeconomic Status on Caregiver Burden

A key finding of the study is the strong and statistically significant association between socioeconomic status and caregiver burden. Caregivers from lower socioeconomic backgrounds reported the highest levels of burden, followed by those from middle SES, while caregivers from higher SES groups reported the lowest burden levels. This pattern is consistent with international and Indian studies demonstrating that socioeconomic disadvantage intensifies caregiving stress through limited access to healthcare, rehabilitation services, assistive devices, and social support (Emerson, 2003; Desai *et al*., 2019) [8, 9].

Low SES caregivers are often required to manage caregiving responsibilities alongside financial insecurity, unstable employment, and inadequate social protection, which compounds emotional and physical strain. In the Indian context, where a significant proportion of healthcare expenditure is out-of-pocket, financial stress related to long-term treatment and rehabilitation further exacerbates caregiver burden. The findings underscore the role of SES as a structural determinant of caregiver well-being rather than merely an individual-level variable.

Intersection of Disability: Type and Socioeconomic Disadvantage

The interaction between disability type and socioeconomic status appears to play a crucial role in shaping caregiver burden. Caregivers of children with ASD from lower SES backgrounds may experience a dual burden arising from behavioural management challenges and limited access to specialized interventions. Similarly, caregivers of children with CP from economically disadvantaged backgrounds face difficulties in accessing physiotherapy, mobility aids, and long-term rehabilitation services, increasing physical strain and emotional distress.

These findings support ecological and stress-process models of caregiving, which emphasize that caregiver outcomes are influenced by both primary stressors (child-related demands) and secondary stressors (socioeconomic constraints) (Pearlin *et al.*, 1990) [23]. The results suggest that interventions aimed at reducing caregiver burden must address not only individual coping strategies but also broader socioeconomic and systemic barriers.

Implications for Intervention and Policy

The findings of the present study have important implications for clinical practice, intervention planning, and public policy. First, routine screening for caregiver burden should be integrated into paediatric and rehabilitation services, particularly for families from lower socioeconomic backgrounds. Second, psychosocial support programs tailored to the specific needs of ASD and CP caregivers are essential, with emphasis on stress management, psychoeducation, and social support.

From a policy perspective, strengthening disability-inclusive healthcare systems, expanding access to affordable rehabilitation services, and providing financial assistance to low-income families may substantially reduce caregiver burden. Community-based rehabilitation and caregiver support groups may be particularly effective in resource-limited settings.

Limitations and Future Directions

While the study provides valuable insights, certain limitations must be acknowledged. The relatively small sample size and cross-sectional design limit the generalizability and causal interpretation of the findings. Future research should employ longitudinal designs with larger and more diverse samples to examine changes in caregiver burden over time. Additionally, qualitative studies may provide deeper understanding of lived caregiving experiences and coping strategies among families from different socioeconomic backgrounds.

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