International Journal of Life Sciences, Biotechnology and Pharma Research Vol. 14, No. 5, May 2025 Online ISSN: 2250-3137
Print ISSN: 2977-0122

DOI: 10.69605/ijlbpr_14.5.2025.20

Original Research

Assessing Caregiver Burden And Coping Strategies Among Parents Of Children With Intellectual Disabilities: A Cross-Sectional Study In North India

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Received Date: 20 March 2025 Acceptance Date: 18 April 2025 Published: 01 May, 2025

ABSTRACT

Background: Caregivers of children with intellectual disabilities often experience significant physical and psychological strain. This study explores the extent of caregiver burden, its impact on caregivers' health, and coping strategies employed to manage these challenges.

Methods: A cross-sectional study was conducted among 96 caregivers of children aged 3–18 years diagnosed with intellectual disability, attending the Psychiatry Department at Rajshree Medical Research Institute, Bareilly. Data were collected through a structured sociodemographic questionnaire and the 13-item Caregiver Strain Index (CSI), alongside assessment of physical and mental health symptoms. Statistical analysis was performed to evaluate associations between burden scores and sociodemographic variables.

Results: The majority of caregivers were female (58.3%) and aged 41–50 years (46.9%). Most belonged to lower socioeconomic strata (46.9%). The mean caregiver burden score was 36.48 ± 7.31, indicating moderate strain, significantly influenced by age, gender, education, and socioeconomic status ($p < 0.05$). Common physical complaints included fatigue (67.7%) and sleep disturbances (60.4%), while anxiety (52.1%) and depression (46.9%) were the predominant mental health symptoms. Social support (62.5%) and religious activities (52.1%) were the most utilized coping strategies, while fewer caregivers accessed professional help (31.2%) or engaged in physical activity (26%).

Conclusion: Caregiver burden among parents of children with intellectual disabilities is considerable and varies with demographic factors. There is a pressing need for integrated, accessible, and culturally sensitive support systems to address both physical and mental health needs of caregivers, especially those from disadvantaged socioeconomic backgrounds.

Keywords: Caregiver burden, Intellectual disability, Mental health, Physical health, Socioeconomic status, Coping strategies, Family support, Cross-sectional study, India, Caregiver strain index

INTRODUCTION

Caregivers of children with intellectual disabilities often endure significant physical and psychological strain (1). Physically, they report high levels of fatigue, sleep disturbances, headaches, and musculoskeletal pain—symptoms that mirror those documented in caregivers of critically ill patients (2,3). Mentally, anxiety and depression are highly prevalent, with up to 70 percent of primary caregivers experiencing clinically significant stress, social withdrawal, and irritability (4). These burdens not only compromise caregiver well-being but can also diminish the quality of care provided, thereby affecting child outcomes (5).

To manage this multifaceted stress, caregivers most commonly turn to social support networks—family, friends, and peer groups—which more than 60 percent find helpful in mitigating emotional exhaustion (6). Religious or spiritual activities are also a frequent coping mechanism, employed by over half of caregivers, reflecting culturally embedded strategies for resilience (7). Far fewer caregivers access professional mental-health services or engage in regular physical exercise (under 35 percent), often due to financial, logistical, or stigma-related barriers (8). Together, these findings underscore the need for integrated support programs that address both the physical and mental health of caregivers—combining community-based networks, culturally sensitive resources, and accessible professional interventions—to sustain caregiver capacity and improve outcomes for children with intellectual disabilities (9).

The present study aims to explore the extent and nature of caregiver burden experienced by parents and other caregivers of children with intellectual disabilities, to examine its impact on their mental and physical health, and to determine the strategies and resources available to support them in managing these challenges.

MATERIAL AND METHODS

This cross-sectional study assessed caregiver burden among parents of children aged 3–18 years who had been diagnosed with intellectual disability according to DSM-5/ICD-11 criteria and who attended the Psychiatry Department at Rajshree Medical Research Institute, Bareilly. Using a purposive sampling technique, we enrolled 96 caregivers over a six-month period—an a priori sample size determined by the formula $N = 3.84 \times P(1–P)/D^2$ (with $P = 0.5$ and $D = 0.1$)—to ensure adequate power for prevalence estimation. Caregivers provided written informed consent and completed a structured sociodemographic questionnaire capturing age, gender, education level, and socioeconomic status, while clinical records were reviewed to confirm each child's diagnosis. Those whose children presented with co-morbid psychiatric conditions or whose own severe physical or cognitive impairments precluded reliable participation were excluded from the study.

To quantify caregiver burden, we administered the 13-item Caregiver Strain Index (CSI), which had been translated into Hindi and validated for linguistic and cultural appropriateness. Trained interviewers conducted face-to-face assessments, recording CSI scores alongside measures of psychological distress. All data were entered into a secure database and analyzed to describe burden severity and its associations with caregiver characteristics. Ethical approval had been obtained in advance from the Institutional Ethics Committee of Rajshree Medical Research Institute, and the study strictly followed ICMR guidelines for human-subject research, with confidentiality and voluntary participation maintained throughout.

RESULTS

Table1:Socio Demographic Profile of Caregivers

Variable	Category	N (%)	p-value
Gender	Male	40(41.7%)	0.018
	Female	56(58.3%)	
Age (years)	30-40	30(31.2%)	0.023
	41-50	45 (46.9%)	
	>50	21(21.9%)	
Education Level	Illiterate	10(10.4%)	0.037
	Primary School	25 (26.0%)	
	Secondary School	40(41.7%)	
	Graduate & Above	21(21.9%)	
Socioeconomic Status(Kuppuswamy Scale)	Lower	45 (46.9%)	0.03
	Middle	40(41.7%)	
	Upper	11(11.5%)	

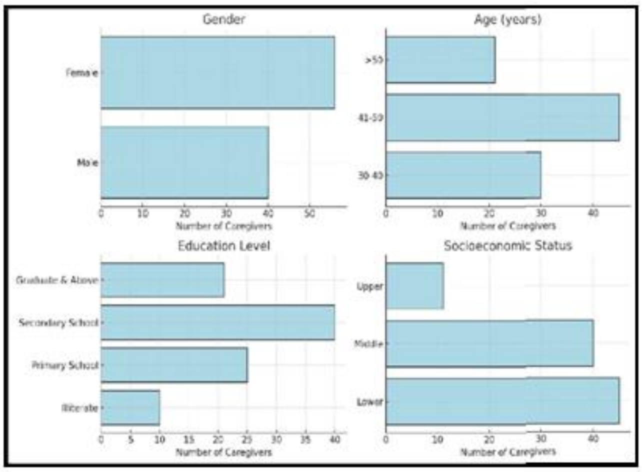

Figure1: Socio Demographic Profile of Caregivers

DOI: 10.69605/ijlbpr_14.5.2025.20

Table 2: Caregiver Burden Score(Mean±SD)

Caregiver Burden Score	Mean ±SD	p-value
Total Score	36.48±7.31	0.044

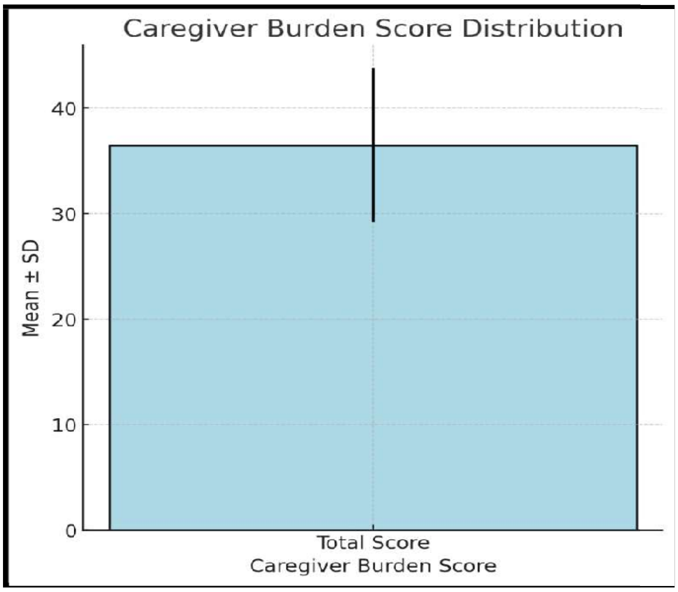

Figure 2:Caregiver Burden Score(Mean ±SD)

Table3: Association of Caregiver Burden with Socioeconomic Status

Socioeconomic Status	Mean ±SD	p-value
Lower	34.63 ±7.19	0.049
Middle	32.19 ±7.02	
Upper	19.77 ±4.48	

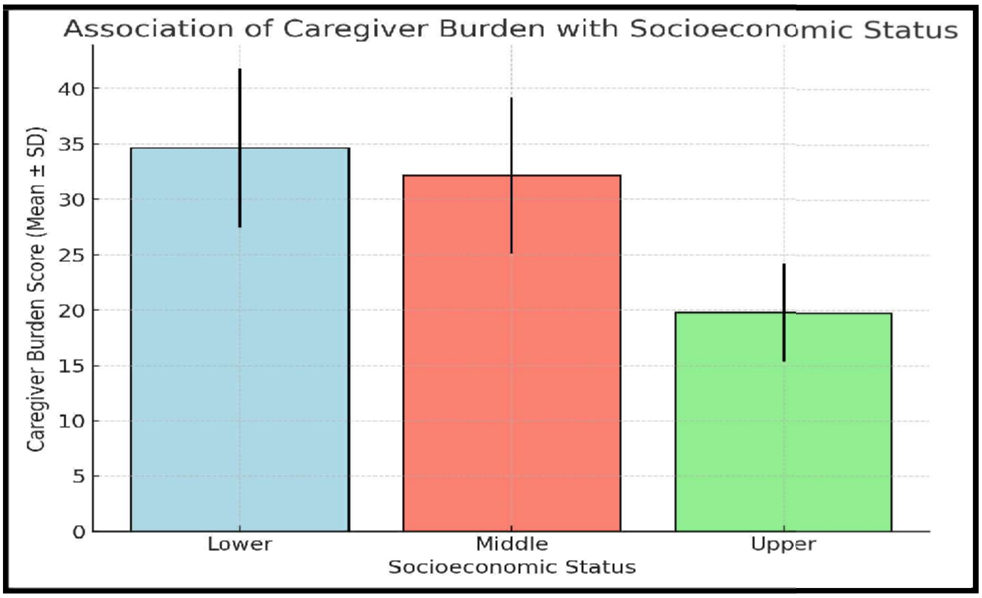

Figure3: Association of Caregiver Burden with Socioeconomic Status

Table 4: Impact of Caregiver Burdenon Physical Health

Physical Health Symptom	N (%)	p-value
Fatigue	65(67.7%)	0.008
Sleep Disturbances	58(60.4%)	
Headaches	40 (41.7%)	
Back Pain	38(39.6%)	

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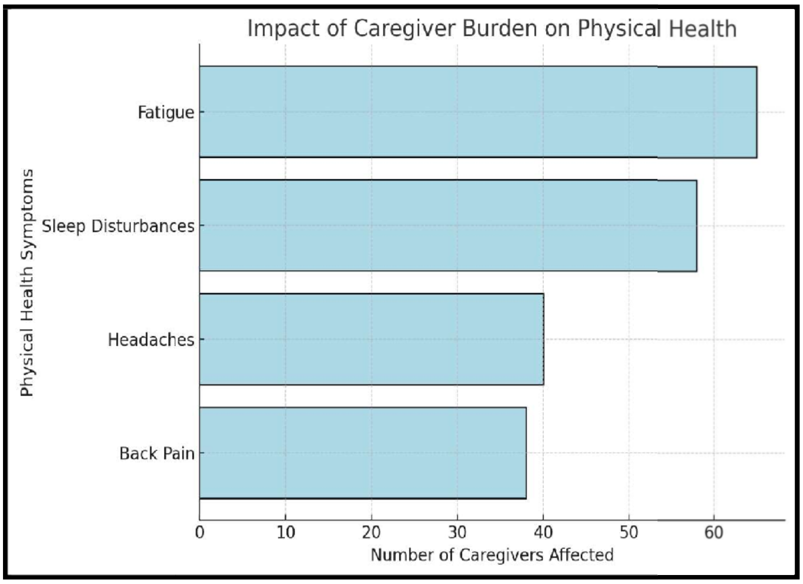

Figure4: Impact of Caregiver Burdenon Physical Health

Table5: Impact of Caregiver Burdenon Mental Health

Mental Health Symptom	N (%)	p-value
Anxiety	50 (52.1%)	0.01
Depression	45 (46.9%)	
Irritability	35 (36.5%)	
SocialWithdrawal	40 (41.7%)	

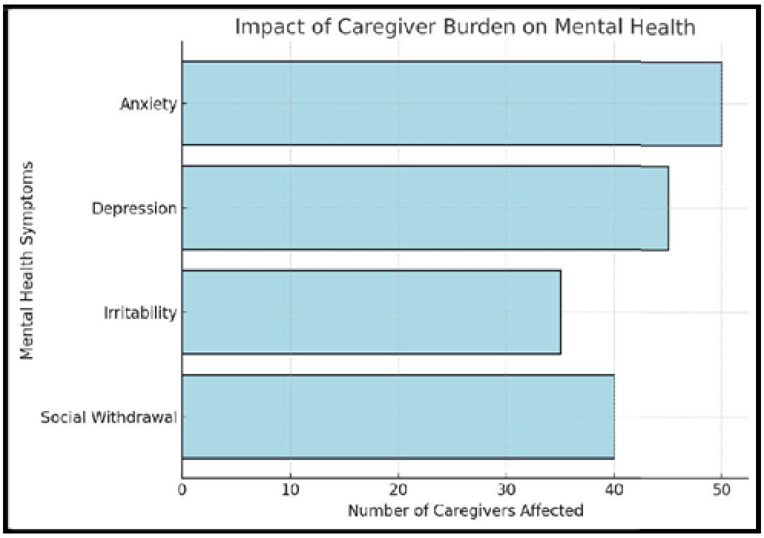

Figure5: Impact of Caregiver Burdenon Mental Health

Table6: Coping Strategies Used by Caregivers

Coping Strategy	N (%)	p-value
Social Support	60(62.5%)	0.011
ReligiousActivities	50 (52.1%)	
ProfessionalHelp	30(31.2%)	
PhysicalActivities	25(26.0%)	

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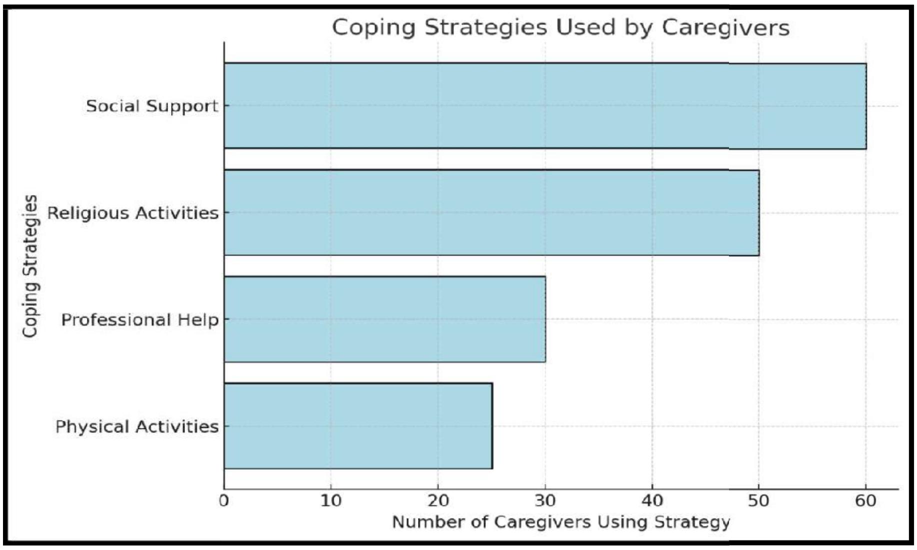

Figure 6: Coping Strategies Used by Caregivers

DISCUSSION

The present study, explored the caregiver burden and assessed its impact on the mental and physical well-being of caregivers, and evaluated the available strategies and resources that help in managing these challenges effectively.

In this study, female caregivers predominated (58.3%), mirroring Sharma et al (2016) findings that women more often assume caregiving roles, especially in critical-care settings (10). Washington et al. (2015) similarly reported higher female involvement in managing critically ill patients, reflecting entrenched societal gender roles (11). Age-wise, most caregivers were 41–50 years old (46.9%), followed by those aged 30–40 years (31.2%), consistent with Subramaniam and Mehta(2024) observation that middle-aged individuals shoulder caregiving due to familial and professional commitments (12). Educational attainment varied significantly (p = 0.037): 41.7% had completed secondary education, while only 21.9% held graduate-level qualifications. Hahn et al. (2020) found that moderate education levels correlate with higher caregiving participation (13), suggesting that targeted health-literacy programs for caregivers with lower formal education could enhance care quality and reduce stress. Socioeconomic status (SES) emerged as a key determinant, with 46.9% of caregivers in the lower-income bracket experiencing significantly greater stress. Perrinet al.(2015) described a disproportionate burden on low-income caregivers due to limited access to healthcare and social support (14), a trend reaffirmed by Austin et al.in 2021 (15). These findings underscore the necessity of tailoring caregiver interventions to address SES-related barriers.

The mean burden score of 36.48 ± 7.31 indicates moderate stress and a significant association (p = 0.044) between burden scores and demographic factors (age, gender, SES) confirms that stress is unevenly distributed and influenced by these variables. High caregiver burden correlated with adverse physical symptoms: fatigue (67.7%), sleep disturbances (60.4%), headaches (41.7%), and back pain (39.6%) (p = 0.008). Matthews et al. (2011) similarly documented fatigue and sleep disruption among critical-care caregivers (16), and Kulkarniet al. (2021) reported musculoskeletal complaints such as back pain (17). Differences in symptom prevalence across studies suggest that care environments and patient conditions modulate physical strain.

Anxiety (52.1%) and depression (46.9%) were the most frequent mental-health symptoms, followed by social withdrawal (41.7%) and irritability (36.5%) (p = 0.01). These rates mirror those reported by sun et al. (2024) emphasis on caregiver isolation (18).

Caregivers most often relied on social support (62.5%) and religious activities (52.1%), with fewer turning to professional help (31.2%) or physical exercise (26.0%) (p = 0.011). Palamaro Munsellet al. (2012) highlighted how caregiver social connections can buffer the negative effects of caregiver strain, especially in families of children with severe emotional disturbances (SED). It highlights that caregiver well-being significantly influences child adjustment and overall family functioning (19).

These findings underscore the multifaceted nature of caregiver burden—demographic factors, physical and mental health impacts, coping patterns, and financial strain all interplay to influence well-being.

CONCLUSION

Caregiver burden in critical-care settings is substantial and unevenly distributed across sociodemographic groups. Systematic support—addressing education, socioeconomic constraints, and both physical and psychological health—is essential to mitigate strain, enhance caregiver resilience, and

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ultimately improve patient and caregiver outcomes.

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