



COMPARATIVE STUDY ON THE CAREGIVER BURDEN OF PATIENTS WITH INTELLECTUAL DEVELOPMENTAL DISORDER AND AUTISM SPECTRUM DISORDER ATTENDING THE CHILD PSYCHIATRY CLINIC OF A TERTIARY CARE HOSPITAL IN KOLKATA

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ABSTRACT

Background: Children with neurodevelopmental disorders often require long-term care and supervision, placing considerable demands on their caregivers. These demands may affect caregivers' emotional well-being and contribute to psychological distress and increased caregiver burden. Although caregiver burden has been studied in autism spectrum disorder (ASD) and intellectual developmental disorder (IDD), comparative data remain limited. The present study aimed to assess anxiety, depression, and caregiver burden among caregivers of children with ASD and IDD and compare these variables between the two groups. A cross-sectional analytical study was conducted among 120 caregivers (60 caregivers of children with ASD and 60 caregivers of children with IDD). Participants were assessed for anxiety, depression, and caregiver burden.

Results: Caregivers of children with ASD and IDD demonstrated significant levels of anxiety, depression, and caregiver burden. Caregivers of children with ASD showed significantly higher burden, anxiety, and depression scores than caregivers of children with IDD.

Conclusion: This study suggests that both ASD and IDD impose substantial caregiving demands; however, caregiver burden, anxiety, and depression were significantly higher among caregivers of children with ASD.

BACKGROUND

Body of background: Autism Spectrum Disorder (ASD) and Intellectual Developmental Disorder (IDD) are among the most common neurodevelopmental disorders encountered in childhood and are associated with significant impairments in adaptive, social, and cognitive functioning. [2,3] ASD is characterised by persistent deficits in social communication and interaction, along with restricted and repetitive patterns of behaviour, interests, or activities. IDD, on the other hand, is characterised by significant limitations in intellectual functioning and adaptive behaviour, affecting conceptual, social, and practical skills required for everyday life.[3,4]

The challenges associated with caring for children with these disorders often extend beyond the affected child and have a substantial impact on family members, particularly primary caregivers. Caregivers frequently face increased responsibilities related to supervision, behavioural management, educational support, and daily care, which may adversely affect their psychological well-being.[5,6] Previous studies have reported elevated levels of stress, anxiety, depression, and caregiver burden among caregivers of children with ASD as well as those caring for children with IDD.[7,8]

Several studies suggest that caregiver burden may be influenced by the severity of symptoms, functional impairment, behavioural difficulties, and level of dependence of the child. While caregivers of children with ASD often report greater stress related to communication deficits and behavioural problems, caregivers of children with IDD may experience challenges associated with long-term dependency and adaptive functioning deficits.[8,9]

Despite the growing body of research on caregiver well-being, comparative studies examining psychological distress and caregiver burden among caregivers of



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children with ASD and IDD remain limited, particularly in the Indian setting.

The present cross-sectional analytical study aims to assess and compare levels of anxiety, depression, and caregiver burden among caregivers of children with ASD and IDD attending the Child Clinic of the Department of Psychiatry, NRS Medical College and Hospital, Kolkata.

Study Objectives: This cross-sectional, analytical study was conducted to assess psychiatric symptoms, specifically anxiety, depression, and caregiver burden among caregivers of children diagnosed with Autism Spectrum Disorder (ASD) and Intellectual Developmental Disorder (IDD). The study also aimed to compare the severity of caregiver burden between the two groups in order to identify differential patterns of psychological distress associated with each disorder.

METHODS

Participants

The study included a total of 120 participants, comprising 60 children diagnosed with Autism Spectrum Disorder (ASD) and 60 with Intellectual Developmental Disorder (IDD). All participants were recruited from the Child Clinic of the Department of Psychiatry, NRS Medical College and Hospital. The study was conducted over a six-month period, from December 2024 to May 2025.

Participants were selected randomly following confirmed diagnoses of ASD and IDD based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5 TR) criteria.

Children with comorbid sensory impairments were excluded from the study. After diagnostic confirmation, eligible participants and their primary caregivers were invited to participate, and informed consent was obtained prior to data collection. The primary caregivers were subsequently assessed for anxiety using the Hamilton Anxiety Rating Scale (HAM-A), for depression using the Hamilton Depression Rating Scale (HAM-D), and for caregiver burden using the 22-item Zarit Burden Interview (ZBI).

Study Tools

- a) DSM-5 TR – For diagnosis of ASD and IDD
- b) HAM – A – For evaluating the anxiety symptoms
- c) HAM- D – For evaluating the depressive symptoms
- d) ZBI – For assessing the Burden amongst the caregivers with the disorders

Statistical Analysis

Data were analysed using non-parametric statistical methods, as the distribution of caregiver burden, anxiety (HAM-A), and depression (HAM-D) scores did not meet assumptions of normality. Descriptive statistics were used to summarise sociodemographic variables. The Mann–Whitney U test was applied to compare continuous outcome variables between the two independent diagnostic groups (ASD vs. IDD). For variables with more than two categorical levels, such as caregiver age groups and socioeconomic status, the Kruskal–Wallis H test was employed to examine differences in burden scores across categories. Categorical variables were compared using frequencies and percentages. Statistical significance was set at $p < 0.05$ for all analyses. Results are presented as mean rank scores along with corresponding p-values to reflect group-wise differences in psychological outcomes.

Ethics Approval and Consent to participate

Prior to the commencement of data collection, ethical approval to conduct the study was obtained from the

Institutional Ethics Committee of NRS Medical College and Hospital. Written informed consent was obtained from all participants before the interviews. Participant confidentiality was strictly maintained by using anonymous questionnaires, conducting interviews individually in a private setting, and securely storing all data in password-protected files accessible only to the research team.

DISCUSSION

The present study assessed and compared caregiver burden, anxiety, and depression among caregivers of children diagnosed with Autism Spectrum Disorder (ASD) and Intellectual Developmental Disorder (IDD). The findings revealed significantly higher levels of caregiver burden, anxiety, and depression among caregivers of children with ASD compared to those caring for children with IDD. These findings are consistent with previous research demonstrating that the social communication deficits, behavioural disturbances, restricted interests, and increased supervision needs associated with ASD contribute substantially to caregiver stress and psychological morbidity. [9,10]

Several studies have reported greater psychological distress among caregivers of children with ASD than among caregivers of children with intellectual and developmental disabilities. Mugno et al. observed significantly higher levels of emotional distress and reduced quality of life among parents of children with autism compared with parents of children with intellectual disability.[8] Similarly, Estes et al. reported that behavioural difficulties and impairments in social functioning were important contributors to parental stress in ASD.[4] The findings of the present study support these observations and suggest that the caregiving demands associated with ASD may be more challenging than those associated with IDD alone.

In the present sample, caregiver burden was significantly associated with caregiver age, gender, and socioeconomic status. Older caregivers and female caregivers reported higher levels of burden than their counterparts. These findings are comparable to those reported in previous studies, which have shown that mothers and primary caregivers often experience greater emotional strain because they assume a larger share of caregiving responsibilities.[5] The higher burden observed among female caregivers in the current study may reflect the continued predominance of caregiving responsibilities among women within many families.

The significantly higher anxiety and depression scores observed among caregivers of children with ASD are in agreement with findings from a meta-analysis by Hayes and Watson, which demonstrated substantially greater parenting stress among parents of children with ASD compared with parents of children with other developmental disabilities.[9] Communication deficits, behavioural challenges, social stigma, and concerns regarding the child's future independence may contribute

to elevated psychological distress in ASD caregivers. Although caregivers of children with IDD also demonstrated significant anxiety and depressive symptoms, the severity was comparatively lower, possibly reflecting differences in symptom presentation and caregiving demands.[8]

Socioeconomic status emerged as an important determinant of caregiver burden in the present study. Caregivers belonging to lower socioeconomic groups reported significantly higher burden scores than those from higher socioeconomic strata. Financial constraints, reduced access to specialised services, transportation difficulties, and limited support systems may exacerbate the challenges associated with caring for a child with a neurodevelopmental disorder. Similar findings have been reported by Raina et al., who highlighted the influence of social and economic factors on caregiver well-being.[6] Interestingly, caregiver burden was not significantly associated with the child's age or sex in either study group. This finding suggests that caregiver distress may be

influenced more by the nature and severity of functional impairments than by demographic characteristics of the child. Previous research has similarly demonstrated that behavioural difficulties and adaptive functioning deficits are stronger predictors of caregiver stress than age or gender alone.[10]

Overall, the present study highlights the considerable psychological burden experienced by caregivers of children with neurodevelopmental disorders, particularly ASD. The significantly higher levels of burden, anxiety, and depression among caregivers of children with ASD underscore the importance of routine caregiver assessment, psychosocial interventions, and accessible support services. Addressing caregiver well-being should be considered an integral component of the comprehensive management of children with ASD and IDD. Future longitudinal studies may help clarify the evolution of caregiver burden over time and identify factors that promote resilience and adaptive coping among caregivers.

RESULTS

Table 1: Association between Caregiver Age, Caregiver Sex, Patient Sex, Patient Age, Socioeconomic Status of the Family and Burden Scores

		N	Mean Rank	P-Value
Burden Score	Age Of The Caregivers			.004
	≤40yrs	62	51.72	
	41ys – 59 Yrs	41	62.46	
	≥ 60 Yrs	17	81.88	
	Sex Of The Caregivers			<0.001
	Male	45	40.28	
	Female	75	72.63	
	Sex Of The Patient			.687
	Male	88	59.43	
	Female	32	63.47	
	Age Of The Patient			.021
	≤ 9 Yrs.	64	52.84	
	≥ 9 Yrs.	56	69.26	
	Socioeconomic Status Of The Family			<0.001
	Lower Class	9	84.72	
	Lower Middle Class	36	76.81	
	Middle Class	49	57.34	
	Upper Middle Class	17	41.56	
	Upper Class	9	32.17	

Table 2: Comparison of Caregiver Burden Scores between IDD and ASD Groups

	CATEGORY	N	Mean Rank	P-Value
Burden Score Of The Caregivers	IDD	60	46.78	<0.001
	ASD	60	77.84	

Table 3: Comparison of Caregiver Anxiety (HAM-A) Scores between IDD and ASD Groups

	CATEGORY	N	Mean Rank	P-Value

HAM-A Score Of The Caregivers	IDD	60	49.64	<0.001
	ASD	60	71.78	

Table 4: Comparison of Caregiver Depression (HAM-D) Scores between IDD and ASD Group

	CATEGORY	N	Mean Rank	P-Value
HAM-D SCORE Of The Caregivers	IDD	60	47.84	<0.001
	ASD	60	70.68	

Table 5: Distribution of Caregiver and Patient Socio-demographic Characteristics across IDD and ASD Groups

Variable	Category	Idd (N=60)	Asd (N=60)	Total (N=120)
Caregiver Sex	Male	24 (40.0%)	15 (25.0%)	39 (32.5%)
	Female	36 (60.0%)	45 (75.0%)	81 (67.5%)
Patient Sex	Male	42 (70.0%)	50 (83.3%)	92 (76.7%)
	Female	18 (30.0%)	10 (16.7%)	28 (23.3%)
Socioeconomic Status (Bg Prasad)	Lower Class	3 (5.0%)	8 (13.3%)	11 (9.2%)
	Lower Middle Class	12 (20.0%)	28 (46.7%)	40 (33.3%)
	Middle Class	28 (46.7%)	18 (30.0%)	46 (38.3%)
	Upper Middle Class	13 (21.7%)	6 (10.0%)	19 (15.8%)
	Upper Class	4 (6.6%)	0 (0%)	4 (3.4%)
Place Of Residence	Urban	34 (56.7%)	22 (36.7%)	56 (46.7%)
	Rural	26 (43.3%)	38 (63.3%)	64 (53.3%)

A total of 120 caregivers were included in the study, comprising 60 caregivers of children with Autism Spectrum Disorder (ASD) and 60 caregivers of children with Intellectual Developmental Disorder (IDD). Female caregivers formed the majority of the study population (67.5%), while male children predominated in both diagnostic groups (76.7%).

Caregiver burden showed significant variation across several sociodemographic characteristics. Older caregivers reported significantly higher burden scores compared to younger caregivers ($p = 0.004$). Female caregivers experienced greater burden than male caregivers ($p < 0.001$). Socioeconomic status was also significantly associated with caregiver burden, with caregivers from lower and lower-middle socioeconomic classes demonstrating higher burden scores than those from middle and upper socioeconomic strata ($p < 0.001$). The sex of the child was not significantly associated with caregiver burden ($p = 0.687$). However, caregiver burden varied significantly according to the child's age ($p = 0.021$).

Comparison between the two study groups revealed significantly greater caregiver burden among caregivers of children with ASD than among caregivers of children with IDD (Median Burden Score: ASD > IDD, $p < 0.001$). Similarly, caregivers in the ASD group had significantly higher anxiety scores on the Hamilton Anxiety Rating Scale (HAM-A) ($p < 0.001$) and higher depression scores on the Hamilton Depression Rating Scale (HAM-D) ($p < 0.001$) compared with caregivers of children with IDD. Overall, the findings indicate that caregiving for children with ASD is associated with significantly greater psychological burden and emotional distress than caregiving for children with IDD. In addition, caregiver burden was influenced by caregiver-related factors, particularly older age, female sex, and lower socioeconomic status, suggesting that these groups may be especially vulnerable to adverse psychological outcomes.

CONCLUSIONS

Body of Conclusions: The findings of the present study indicate that caregivers of children with neurodevelopmental disorders experience substantial psychological burden. Caregivers of children with Autism Spectrum Disorder (ASD) were found to have significantly higher levels of caregiver burden, anxiety, and depression compared to caregivers of children with Intellectual Developmental Disorder (IDD). These findings suggest that the unique social, behavioural, and communication difficulties associated with ASD may place additional demands on caregivers, adversely affecting their psychological well-being.

The study also highlights the influence of sociodemographic factors on caregiver outcomes. Greater burden was observed among older caregivers, female caregivers, and those belonging to lower socioeconomic groups, indicating that caregiving experiences are shaped not only by the child's condition but also by the caregiver's social and economic circumstances.

Taken together, these findings emphasise the need for routine assessment of caregiver mental health in clinical settings. Interventions aimed at reducing caregiver stress, improving access to support services, and strengthening coping resources may contribute to better outcomes for both caregivers and children. A family-centred approach that acknowledges and addresses caregiver needs should form an essential component of the management of children with ASD and IDD.

Recommendations

The findings of the present study emphasize the importance of addressing the needs of caregivers alongside the clinical management of children with Autism Spectrum Disorder (ASD) and Intellectual Developmental Disorder (IDD). Given the significantly higher levels of burden, anxiety, and depression observed among caregivers of children with ASD, targeted interventions for this group are particularly warranted. Regular assessment of caregiver well-being should be incorporated into routine child psychiatry services to facilitate early identification of psychological distress.

Interventions such as psychoeducation, caregiver training programmes, counselling, and stress-management strategies may help caregivers better cope with the demands associated with long-term caregiving. Particular attention should be paid to caregivers who are older, female, or from economically disadvantaged backgrounds, as these groups appear to be at greater risk of experiencing caregiver burden.

Efforts to strengthen community support systems, improve access to mental health services, and promote caregiver support networks may further enhance coping and reduce the sense of isolation often reported by caregivers. At a broader level, policies and service models for children with neurodevelopmental disorders should adopt a family-oriented approach that recognises caregiver well-being as an essential component of effective and comprehensive care.

Study Limitation(s): Certain limitations of the present study need to be considered while interpreting the findings. As the study employed a cross-sectional design, it was not possible to establish temporal or causal relationships between caregiving responsibilities and the psychological difficulties experienced by caregivers. The study was conducted in a single tertiary care teaching hospital, and therefore the findings may not be representative of caregivers in other healthcare settings or in the general community.

Another limitation relates to the use of questionnaire-based assessments, which depend on participants' responses and may be influenced by recall bias, underreporting, or the tendency to provide socially acceptable answers. This is particularly relevant in the context of psychological symptoms, where stigma and personal beliefs may affect reporting.

The study also did not examine several factors that could potentially influence caregiver burden and emotional well-being, such as the severity of the child's illness, behavioural problems, family support systems, coping mechanisms, caregiver resilience, and availability of rehabilitation or community-based services. Inclusion of these variables might have provided a more detailed understanding of the factors contributing to caregiver distress.

Future studies involving larger samples from multiple centres and employing longitudinal follow-up designs may help to clarify the evolving nature of caregiver burden over time and identify factors that protect against adverse psychological outcomes among caregivers of children with neurodevelopmental disorders.

Abbreviations

- a) DSM-5 TR- Diagnostic and Statistical Manual – 5 Text Revision (Fifth Edition)
- b) ASD – Autism Spectrum Disorder
- c) IDD – Intellectual Developmental Disorder
- d) ZBI – Zarit Burden Interview Scale
- e) HAM –A – Hamilton Anxiety Rating Scale
- f) HAM- D – Hamilton Depression Rating Scale

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