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Financial and Emotional Burden on Parents of Children with Attention- Deficit/Hyperactivity Disorder: A Cross-Sectional Study from Kashmir, India

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Abstract

Background: Attention-deficit/hyperactivity disorder (ADHD) affects families as much as the children it is diagnosed in, yet no study has quantified this burden among caregivers in Kashmir, a region already shaped by decades of conflict-related psychological stress. We conducted a cross-sectional study of 127 primary caregivers of children aged 6–12 years with DSM-5-confirmed ADHD at a tertiary child psychiatry service in Kashmir, assessing financial burden with a structured cost inventory and emotional burden with the Parenting Stress Index–Short Form (PSI-SF) and the Zarit Burden Interview (ZBI).

Results: Mean annual direct cost was INR 19,800 (≈USD 239); including indirect costs, mean total financial burden was INR 30,800 (≈USD 371) per child. Mean PSI-SF score was 82.0 (SD 7.4; 95% CI 80.7–83.3). Approximately half of caregivers (64/127, 50.4%) reported significant emotional distress, 51/127 (40.2%) met criteria for probable depression or anxiety, and 72/127 (56.7%) reported strain on family relationships. PSI-SF scores correlated moderately with emotional distress ($r = 0.57$, 95% CI 0.44–0.68, $p < 0.001$). Financial burden did not differ significantly by household income level ($\chi^2(1) = 0.41$, $p = 0.52$).

Conclusions: Caregivers of children with ADHD in Kashmir carry a burden that is financially modest in absolute terms but psychologically substantial, and that does not appear to spare higher-income households. Family-centred psychological and financial support deserves a place in regional ADHD services.

INTRODUCTION

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common neurodevelopmental conditions of childhood, with a pooled global prevalence near 5.3%.[1] Indian estimates range from 5% to 10%, skewed toward urban areas — a pattern that likely reflects better case detection rather than a true urban–rural difference.[2,3] Inattention, hyperactivity, and impulsivity are its core features, and for many children these symptoms persist well into adulthood, disrupting school, work, and relationships along the way.[1]

ADHD is usually described as a child's disorder, but its effects rarely stop with the child. Caregivers in high-income countries report elevated stress, higher rates of psychological illness, disrupted employment, and real out-of-pocket costs.[4,5] In lower-resource settings these pressures do not ease — they compound, against a backdrop of thin public mental health infrastructure, little insurance coverage, persistent stigma, and too few specialists.[6]

Kashmir adds a further layer that most burden-of-illness studies simply do not encounter: decades of armed conflict have left the population with unusually high rates of psychological morbidity, worn down health-seeking behaviour, and weakened the informal support networks families would otherwise lean on.[7] Whether and how this background stress interacts with the ordinary demands of raising a child with

ADHD has not, to our knowledge, been studied here — no peer-reviewed data exist on the financial or emotional cost borne by these families.

This study set out to do three things: estimate the direct and indirect financial costs incurred by parents of children with ADHD attending a tertiary child psychiatry service in Kashmir; characterize caregivers' emotional burden using validated instruments; and examine whether burden varies by household income. The intention throughout has been practical — data that can inform how services and policy respond to these families, not just describe them.

METHODS

Study Design and Setting

This cross-sectional study was conducted at the Department of Child Psychiatry, Institute of Mental Health and Neurosciences–Kashmir (IMHANS-K), Government Medical College, Srinagar, between May 2025 and May 2026. IMHANS-K is the only tertiary-level government mental health facility in the Kashmir Valley, serving a catchment population of roughly 7 million. Reporting follows the STROBE guideline for cross-sectional studies.[17]

Participants

We used consecutive sampling. Children were eligible if they were 6–12 years old and had a confirmed DSM-5 diagnosis of ADHD, made by a consultant child psychiatrist on the basis of clinical interview and the ADHD Rating Scale–IV (ADHD-RS-IV; Cronbach's α 0.86–0.92).[8] The primary caregiver — the adult carrying the main day-to-day responsibility for the child — was the study participant for burden assessment.

We excluded children with co-occurring intellectual disability (IQ < 70), autism spectrum disorder, psychosis, or a major neurological disorder, and excluded caregivers with a diagnosed severe mental disorder that would compromise reliable self-report, or who could not provide written informed consent.

A total of 127 caregiver–child dyads were enrolled over the 12-month study period. Based on an a priori power calculation (α = 0.05, two-tailed, power = 80%), a minimum of 24 dyads was needed to detect the expected primary correlation (r = 0.55) between parenting stress and caregiver emotional distress, and 84 dyads to detect a conservative medium effect size (r = 0.30). Our final sample (N = 127) meets these requirements, offering adequate power (> 99% for r = 0.55; 92% for r = 0.30) for primary bivariate testing and allowing for planned subgroup comparisons across clinical and demographic variables.

Data Collection Instruments

A researcher-developed semi-structured proforma captured sociodemographic and clinical data: child age, sex, ADHD subtype, duration of illness, and caregiver age, sex, education, occupation, and household income.

Financial burden was assessed with a structured cost inventory adapted from the WHO-CHOICE costing framework,[9] covering direct medical costs (consultations, medication, investigations), direct non-medical costs (therapy, special educational support, assistive materials), and indirect costs (income foregone through caregiving, transport). Costs were recorded in Indian Rupees and converted to USD at the prevailing rate at the time of analysis (1 USD ≈ INR 83).

Emotional burden was assessed with two validated instruments. The Parenting Stress Index–Short Form (PSI-SF; 36 items, range 36–180, clinical concern at or above the 90th percentile) measures stress arising from the demands of parenting.[10] The Zarit Burden Interview (ZBI; 22 items, range 0–88; mild 21–40, moderate 41–60, severe above 60) captures caregiver strain across emotional distress, social isolation, and family-relationship impact.[11] Both instruments have documented validity in South Asian populations.[12]

Statistical Analysis

Data were analysed in IBM SPSS Statistics version 26.0. Continuous variables are reported as mean ± SD with 95% confidence intervals; categorical variables as frequency and percentage. Shapiro-Wilk testing was used to assess normality. Pearson's correlation coefficient examined the association between PSI-SF total score and the ZBI emotional distress subscale. Because expected cell frequencies fell below 5, chi-square was used to test the association between income strata and above-median financial burden. Significance was set at $p < 0.05$, two-tailed. The dataset was complete, so no imputation was required.

Ethical Considerations

The study was approved by the Institutional Ethics Committee of Government Medical College, Srinagar [INSERT: committee name and approval reference number]. Written informed consent was obtained from all caregivers before enrolment; assent was sought from children aged 8 years or older. Data were anonymised before analysis. The study followed the 2013 revision of the Declaration of Helsinki.

Use of Artificial Intelligence

Generative AI (Claude, Anthropic) assisted with language editing and manuscript formatting for this submission. The authors verified all data, analyses, and conclusions and take full responsibility for the manuscript's content. AI was not involved in study design, data collection, or analysis.

RESULTS

Demographic and Clinical Characteristics

A total of 127 caregiver–child dyads were enrolled; none withdrew or were excluded after enrolment. Children had a mean age of 8.3 years (SD 1.5; range 6–12), and two-thirds were male (n = 85, 66.9%) in line with the known male predominance in ADHD. Most caregivers were mothers (n = 93, 73.2%), with a mean age of 37.4 years (SD 4.2). Table 1 summarises the sociodemographic and clinical parameters of the sample.

Table 1
Sociodemographic Characteristics of Child–Caregiver Dyads (N = 127)

Characteristic	n (%)	Mean ± SD
Child age (years)	—	8.3 ± 1.5
Child sex: Male	85 (66.9%)	—
Child sex: Female	42 (33.1%)	—
Caregiver age (years)	—	37.4 ± 4.2
Caregiver age 30–35 years	42 (33.1%)	—
Caregiver age 36–40 years	51 (40.2%)	—
Caregiver age 41–45 years	34 (26.8%)	—
Household income < INR 30,000/month	51 (40.2%)	—
Household income ≥ INR 30,000/month	76 (59.8%)	—
ADHD subtype: Combined	68 (53.5%)	—
ADHD subtype: Inattentive	38 (29.9%)	—
ADHD subtype: Hyperactive-impulsive	21 (16.5%)	—
Duration of symptoms prior to diagnosis (months)	—	18.6 ± 8.9

ADHD = attention-deficit/hyperactivity disorder; SD = standard deviation.

Financial Burden

Direct costs constituted 64.3% of total annual expenditure (mean INR 19,800; ~USD 239), while indirect costs — chiefly income lost to caregiving — accounted for 35.7% (mean INR 11,000; ~USD 133) (Table 2). Medical consultations/medications and lost caregiver income were the two largest single cost components, each averaging INR 8,800 annually (28.6% of total burden apiece). A Pearson chi-square test revealed no significant association between household income strata (< INR 30,000 vs. ≥30,000) and experiencing an above-median financial burden ($\chi^2(1, N = 127) = 0.41$, $p = 0.52$), indicating that the financial impact of managing ADHD is substantial across both lower and higher socioeconomic groups.

Table 2
Annual Financial Burden: Direct and Indirect Costs (N = 127)

Cost Category	Mean Annual Cost (INR)	Approx. USD
Medical consultations and medications	8,800	~ 106
Psychotherapy and behavioural therapy	6,600	~ 80
Educational support and remediation	4,400	~ 53
Subtotal — direct costs	**19,800**	**~ 239**
Lost caregiver income	8,800	~ 106
Transportation to appointments	2,200	~ 27
Subtotal — indirect costs	**11,000**	**~ 133**
Total annual financial burden	**30,800**	**~ 371**

Currency conversion at INR 83 = USD 1 (prevailing rate at time of analysis).

Emotional and Psychological Burden

Mean PSI-SF score remained 82.0 (SD 7.4; 95% CI 80.7–83.3) — below the published 90th-percentile clinical cutoff of 90, but within the 75th–85th percentile range, which we interpret as clinically meaningful elevation in parenting stress rather than a reassuring result. On the ZBI, 64 of 127 caregivers (50.4%; 95% CI 41.8–58.9) were classified as reporting significant emotional distress; 51 (40.2%; 95% CI 32.0–48.9) met criteria for probable depression or anxiety; and 72 (56.7%; 95% CI 48.0–65.0) reported a negative impact on family relationships, including marital and sibling dynamics (Table 3). PSI-SF total score correlated moderately with the ZBI emotional distress subscale ($r = 0.57$, 95% CI 0.44–0.68, $p < 0.001$), demonstrating that caregivers experiencing higher parenting stress also reported significantly greater emotional distress.

Table 3
Emotional Burden Assessment: Zarit Burden Interview Domains (N = 127)

Domain	n	% (95% CI)
Significant emotional distress	64	50.4 (41.8–58.9)
Probable depression or anxiety symptoms	51	40.2 (32.0–48.9)
Adverse impact on family relationships	72	56.7 (48.0–65.0)
ZBI mean total score (SD)	—	31.8 ± 9.6

95% CI calculated using Wilson's method for proportions. ZBI = Zarit Burden Interview.

DISCUSSION

This study provides a comprehensive assessment of the financial and emotional burden faced by parents of children with ADHD in Kashmir. Three central findings emerge: the financial burden is heavy relative to local household income despite modest absolute dollar figures; financial strain crosses socioeconomic lines without significant variation by income tier; and caregiver emotional distress registers at a level of clear clinical concern. Set against local benchmarks, an annual expenditure of INR 30,800 (~ USD 371) represents a major financial outlay. The National Sample Survey places median monthly per-capita consumption expenditure in Jammu & Kashmir at roughly INR 2,500–3,000.[13] On that basis, ADHD-related costs equate to approximately 10.3–12.3 months of per-capita spending — essentially a full year's typical budget per person. While direct cross-national comparisons must account for regional purchasing power, this relative economic load is proportionally heavier on local household budgets than figures reported in high-income settings (e.g., US annual estimates of USD 1,574–2,097), and it extends the sole prior Indian cost-of-illness estimate for ADHD[14] to a conflict-affected setting, underscoring the necessity of locally grounded cost data for regional policy planning. The absence of income-stratified variation is worth sitting with. It probably does not mean rich and poor families spend the same amount; more likely, lower-income families are simply forgoing or delaying costlier interventions — therapy in particular — so their reported spending understates their real need, while better-off families access more of what's available. Future work should pair expenditure data with a direct measure of unmet treatment need.

A mean PSI-SF score of 82 places this cohort in the 75th–85th percentile — elevated, though short of the formal clinical threshold. This tracks with Theule and colleagues' 2013 meta-analysis, which found a medium-to-large effect size for parenting stress in ADHD families versus controls (d = 0.86, 95% CI 0.74–0.98).[5] Whether Kashmir's background of conflict-related stress adds to, or interacts with, the ordinary demands of ADHD caregiving is a question this study cannot answer, but frameworks such as Conservation of Resources theory, which conceptualises stress as arising from the actual or threatened loss of psychological, social, and material resources, offer one avenue for future investigation.[15]

More than half of caregivers (56.7%) reported strain on family relationships, which lines up with earlier work on ADHD-linked marital tension, sibling conflict, and social withdrawal.[16] Taken together, this argues for treating ADHD as a family-systemic issue in clinical planning, not just a child's diagnosis to be managed in isolation.

CONCLUSIONS

Parents of children with ADHD in the Kashmir Valley carry financial and emotional burdens that cross socioeconomic lines. With elevated parenting stress, probable anxiety or depression, and family strain present in roughly half of caregivers, ADHD must be addressed as a family-systemic public health priority. Integrated clinical care that combines evidence-based child management with caregiver psychological support and financial counselling is strongly indicated. Furthermore, these findings

support the formal inclusion of ADHD within national mental health initiatives such as Tele-MANAS, alongside subsidised medication schemes and expanded government-funded behavioral therapy access through tertiary centers like IMHANS-K.

Abbreviations

ADHD
Attention-Deficit/Hyperactivity Disorder
ADHD-RS-IV
ADHD Rating Scale–IV
CI
Confidence Interval
DSM-5
Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
IMHANS-K
Institute of Mental Health and Neurosciences–Kashmir
INR
Indian Rupee
NSS
National Sample Survey
PSI-SF
Parenting Stress Index–Short Form
SD
Standard Deviation
STROBE
Strengthening the Reporting of Observational Studies in Epidemiology
USD
United States Dollar
WHO-CHOICE
World Health Organization — Choosing Interventions that are Cost-Effective
ZBI
Zarit Burden Interview

Declarations

Ethics approval and consent to participate

The study was approved by the Institutional Ethics Committee of Government Medical College, Srinagar, and Ref No: IRBGMC-SGR/PSY/1014. Written informed consent was obtained from all caregivers before enrolment; assent was sought from children aged 8 years or older. The study followed the 2013 revision of the Declaration of Helsinki.

Consent for publication

Not applicable. This manuscript does not contain any individual person's data in any form (including individual details, images, or videos).

Competing interests

The authors declare that they have no competing interests.

Authors' information

Not applicable.

REPORTING GUIDELINE (SUPPLEMENTARY ONLINE MATERIAL)

Name: STROBE Statement for cross-sectional studies

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Author Contribution

Mohd Abrar Ahmad Guroo conceived and designed the study, supervised data collection, performed the statistical analysis, and drafted the manuscript. Zaid Ahamd Wani, Junaid Nabi, Deeba Nazir and Bilal Ahmed Teli contributed to patient recruitment, data collection, and critical revision of the manuscript for important intellectual content. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

References

1. Polanczyk GV, Salum GA, Sugaya LS, Caye A, Rohde LA (2015) Annual research review: A meta-analysis of the worldwide prevalence of mental disorders in children and adolescents. J Child Psychol Psychiatry 56:345–365
2. Sagar R, Dandona R, Gururaj G et al (2020) The burden of mental disorders across the states of India: the Global Burden of Disease Study 1990–2017. Lancet Psychiatry 7:148–161
3. Fayyad J, Sampson NA, Hwang I et al (2017) The descriptive epidemiology of DSM-IV Adult ADHD in the World Health Organization World Mental Health Surveys. ADHD Atten Deficit Hyperact Disord 9:47–65
4. Doshi JA, Hodgkins P, Kahle J et al (2012) Economic impact of childhood and adult attention-deficit/hyperactivity disorder in the United States. J Am Acad Child Adolesc Psychiatry 51:990–1002
5. Theule J, Wiener J, Tannock R, Jenkins JM (2013) Parenting stress in families of children with ADHD: A meta-analysis. J Emotional Behav Disord 21:3–17
6. Lund C, Docrat S, Abdulmalik J et al (2020) Household costs and economic burden of mental, neurological and substance use disorders in sub-Saharan Africa. Trop Med Int Health 25:260–271
7. Margoob MA, Dutta KS, Majid A et al (2006) Prevalence of PTSD in the conflict-ridden Kashmir Valley: a community-based study. J Pakistan Psychiatric Soc 3:14–17
8. DuPaul GJ, Power TJ, Anastopoulos AD, Reid R (1998) ADHD Rating Scale-IV: Checklists, Norms, and Clinical Interpretation. Guilford Press, New York
9. Tan-Torres Edejer T, Baltussen R, Adam T et al (2003) WHO Guide to Cost-Effectiveness Analysis. World Health Organization, Geneva
10. Abidin RR (1995) Parenting Stress Index-Short Form: Test Manual. Psychological Assessment Resources, Odessa, FL
11. Zarit SH, Reever KE, Bach-Peterson J (1980) Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 20:649–655
12. Bhatia MS, Srivastava S, Gautam P, Bhatia S (2020) Adaptation and validation of the Zarit Burden Interview in Indian caregivers of persons with dementia. Asian J Psychiatr 54:102433
13. National Sample Survey Office (2022) Household Consumer Expenditure Survey (NSS 77th Round). Ministry of Statistics and Programme Implementation, New Delhi
14. Bhatt AH, Bhatt MS, Arora D, Shukla S (2021) Cost of illness in attention-deficit hyperactivity disorder in India. Indian J Psychiatry 63:465–470
15. Hobfoll SE (2001) The influence of culture, community, and the nested-self in the stress process: Advancing Conservation of Resources Theory. Appl Psychol 50:337–421

16. Johnston C, Mash EJ (2001) Families of children with attention-deficit/hyperactivity disorder: review and recommendations for future research. Clin Child Fam Psychol Rev 4:183–207
17. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP (2007) The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. Lancet 370:1453–1457