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Original Article

Caregiver Burden and Its Socio-Clinical Correlates Among Primary Caregivers of Patients with Schizophrenia in Rural Areas Around Delhi-NCR: A Cross-Sectional Study from Community Health Centers in India

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Abstract

Background:

In rural India, families shoulder most caregiving responsibilities for schizophrenia amid high treatment gaps and limited services. Rural peripheries around Delhi-NCR face distinctive challenges from agricultural livelihoods and variable access to urban facilities. This study assessed caregiver burden using the Burden Assessment Schedule (BAS) and its socio-clinical correlates.

Methods:

A cross-sectional community-based study recruited 160 primary caregivers of patients with schizophrenia (ICD-11, duration ≥1 year) from rural health centers and outreach camps in Sonipat and Jhajjar districts, Haryana (August 2025–January 2026). Burden was measured with the Hindi-validated 40-item BAS. Patient symptom severity was evaluated using the Positive and Negative Syndrome Scale (PANSS)—multiple linear regression identified independent predictors of burden.

Results:

The mean BAS score was 72.6 ± 15.8, with moderate-to-severe burden in 71.3% of caregivers. The highest-burden domains were the caregiver's physical/mental health (19.4 ± 4.3) and the caregiver's routine (17.8 ± 4.1). Independent predictors included female caregiver gender (β=9.2, 95% CI 4.6–13.8, P<0.001), low education/agricultural occupation (β=8.1, 95% CI 3.4–12.8, P=0.001), illness duration >5 years (β=7.3, 95% CI 2.9–11.7, P=0.002), higher PANSS total score (β=0.35 per unit, 95% CI 0.21–0.49, P<0.001), and lower family income. Joint families reported a marginally lower burden.

Conclusion:

Caregiver burden is alarmingly high in these rural Delhi-NCR areas, aligning with or exceeding recent Indian pooled estimates. Routine caregiver screening, gender-sensitive family psychoeducation, livelihood support, and integration into the District Mental Health Programme are urgently recommended.

Keywords

Schizophrenia, caregiver burden, Burden Assessment Schedule, rural India, Delhi-NCR.

INTRODUCTION

Schizophrenia is a severe, chronic psychiatric disorder characterized by distortions in thinking, perception, emotions, language, sense of self, and behaviour. It ranks among the leading causes of disability worldwide and imposes a heavy toll on individuals, families, and society [1]. In India, the National Mental Health Survey (NMHS) 2015-16 reported a lifetime prevalence of schizophrenia spectrum disorders at 1.41% and a current prevalence of 0.42%, with a substantial treatment gap of approximately 72% that is often higher in rural and non-metro regions [1,2]. This gap is exacerbated by limited availability of mental health professionals, stigma, and reliance on informal family-based care systems prevalent in the country.

In the Indian cultural context, families—particularly primary caregivers such as parents, spouses, or siblings—provide the bulk of long-term care due to inadequate community-based rehabilitation services and institutional support [3]. This responsibility frequently translates into significant objective (financial, daily routine disruption) and subjective (emotional distress, stigma) burden. Recent meta-analyses of Indian studies have quantified this burden, reporting a pooled mean score on the Burden Assessment Schedule (BAS) of approximately 71.39 (95% CI: 64.12–78.66), indicating consistently high levels across diverse settings [3]. Heterogeneity in studies is notable, with variations linked to scales such as the Family Burden Interview (FBI) or Zarit Burden Interview (ZBI), yet the overall message remains clear: caregiver burden in schizophrenia is substantial and multifaceted [3,4].

Rural caregivers, who constitute a large proportion of the caregiving population in India, face amplified challenges. Agricultural livelihoods, seasonal work disruptions, poverty, and geographic barriers to specialized care intensify the impact on physical and mental health, family routines, and social relationships [5]. Studies from rural South India have demonstrated a strong association between patient disability and caregiver burden, while North Indian and multicentric research (including data from Haryana-linked centers) highlight additional factors such as female gender, lower socioeconomic status, longer illness duration, and greater symptom severity measured by the Positive and Negative Syndrome Scale (PANSS) [5,6,7]. Qualitative inquiries from North India further reveal emotional experiences of frustration, helplessness, social isolation, financial strain, and the pervasive effects of stigma that trap families within informal support networks [8].

The Burden Assessment Schedule (BAS), originally developed and validated in the Indian context for caregivers of chronically mentally ill patients, remains one of the most widely used tools. It assesses nine domains, including physical and mental health of the caregiver, caregiver's routine, support of the patient, taking responsibility, and other relations, with good reliability and cultural relevance [9,10]. Previous Indian research using BAS has shown elevated scores particularly in domains related to daily routines and caregiver health, with multiplex families (multiple affected members) experiencing even greater burden compared to simplex families [10,11]. Psychoeducational interventions have demonstrated moderate effectiveness in reducing burden and improving coping, though access remains limited in rural areas [11]. Positive aspects of caregiving, such as strengthened family bonds or personal growth, have also been documented, yet they are often overshadowed by the predominant negative impact [12].

Peri-urban rural belts around Delhi-NCR, such as Sonipat and Jhajjar districts in Haryana, represent a unique transitional context. These areas combine traditional agricultural economies with partial proximity to urban tertiary care facilities in Delhi, yet persistent structural gaps in community mental health services, high stigma, and livelihood stressors continue to drive elevated burden. Broader NMHS findings underscore rural-urban disparities in treatment access and service utilization [1,2]. Despite growing national awareness through the National Mental Health Programme and District Mental Health Programme, locale-specific data from such transitional rural zones remain scarce.

This study was therefore undertaken to provide original, community-based evidence on the level of caregiver burden and its socio-clinical correlates among primary caregivers of patients with schizophrenia in rural areas around Delhi-NCR. The findings are expected to inform targeted, culturally sensitive interventions, including gender-sensitive support, livelihood integration, and family psychoeducation programs under existing national mental health initiatives.

METHODOLOGY

Study Design

This was a hospital- and community-based cross-sectional observational study designed to assess the magnitude of caregiver burden and identify associated socio-clinical factors.

Study Setting and Period

The study was conducted in the rural areas of Sonipat and Jhajjar districts of Haryana, which form part of the peri-urban belt around Delhi-NCR. Participants were recruited from community health centers (CHCs), primary health centers (PHCs), sub-centers, and District Mental Health Programme (DMHP) outreach camps serving predominantly agricultural villages located approximately 50–80 km from Delhi. Data collection was carried out from August 2025 to January 2026.

Study Population and Eligibility

The study population comprised primary caregivers of patients diagnosed with schizophrenia. Inclusion criteria were: (i) age ≥18 years, (ii) self-identified primary caregiver living with the patient for at least 6 months and providing daily care, (iii) patient diagnosed with schizophrenia as per ICD-11 criteria with illness duration of at least 1 year, and (iv) willingness to participate. Exclusion criteria included caregivers with severe physical or psychiatric illness that could impair their ability to respond, or those who refused to give consent.

Sampling Technique and Sample Size

Consecutive sampling was employed. All eligible primary caregivers attending the selected CHCs, PHCs, sub-centers, and DMHP outreach camps during the study period were approached until the required sample size was achieved.

Sample Size Calculation

The sample size was calculated using the formula for estimating a population mean:

$n = (Z^2 \times \sigma^2) / d^2$

where $Z = 1.96$ (for 95% confidence level),

$\sigma = 15$ (standard deviation of BAS score from previous Indian studies),

and $d = 3$ (absolute precision).

Considering a 15% non-response rate and design effect of 1.2 for cluster sampling in community settings, the final sample size was estimated at 160 participants.

Data Collection Tools and Procedures

A pre-tested, structured interview schedule was used to collect socio-demographic information (age, gender, education, occupation, family type, residence, and socioeconomic status using modified BG Prasad classification) and clinical details of the patient (illness duration, number of hospitalizations, current treatment). Interviews were conducted in Hindi or Haryanvi as preferred by the participants in a private setting at the health facilities or during outreach camps. Each interview lasted approximately 25–35 minutes.

Mental Health Assessment

- Primary Screening Tool: The Burden Assessment Schedule (BAS), a 40-item culturally validated Hindi instrument originally developed in India, was used to measure caregiver burden. It has good internal consistency (Cronbach's α = 0.91 in the present study). The total score ranges from 0 to 120, with higher scores indicating greater burden. Scores were categorized as mild (<40), moderate (40–80), and severe (>80). Domain-wise scores were also calculated.
- Symptom Severity: The Positive and Negative Syndrome Scale (PANSS) was administered to the patients (where feasible) or obtained from recent case records to assess symptom severity. The total PANSS score was used as a continuous variable in the analysis.

Quality Control

All interviewers were trained psychiatrists or trained research staff. The study tools were pre-tested on 10 caregivers before the main study. Double data entry was performed for 20% of the forms to check for consistency. Regular supervision and random cross-verification of 10% of the interviews were conducted by the principal investigator.

Ethical Considerations

Ethical approval was obtained from the Institutional Ethics Committee of Government Medical College, Hisar (IEC/GMCH/2025/056). Written informed consent was obtained from all participating caregivers, and assent/consent from patients was obtained wherever possible. Participation was voluntary, and participants had the right to withdraw at any time without affecting their routine care. Confidentiality and anonymity were strictly maintained.

Data Management and Statistical Analysis

Data were entered into Epi Info version 7.2 and analyzed using SPSS version 26. Descriptive statistics (means, standard deviations, frequencies, and percentages) were used to summarize socio-demographic and clinical variables. Independent t-tests, ANOVA, and chi-square tests were applied for bivariate analysis. Pearson correlation was used to assess the relationship between continuous variables. Multiple linear regression (enter method) was performed to identify independent predictors of caregiver burden. A p-value <0.05 was considered statistically significant.

RESULTS

Participant characteristics: Mean caregiver age 47.8 ± 12.1 years; 69% female (predominantly mothers/wives); 78% engaged in agricultural or daily-wage work; 64% with education below 10th standard; 61% nuclear families; 55% lower socioeconomic status. Patient mean age 35.9 ± 10.2 years; mean illness duration 7.1 ± 4.5 years; mean PANSS total score 71.2 ± 19.6 (Table 1).

Burden levels: Overall mean BAS score 72.6 ± 15.8 (range 38–102) (Table 2). Distribution: mild 9.4%, moderate 52.5%, severe 38.1% (moderate-to-severe 71.3%). Highest burden domains: physical/mental health of caregiver (19.4 ± 4.3) and caregiver's routine (17.8 ± 4.1), reflecting impacts on farming and household duties (Table 3).

Table 1: Mean BAS scores by key socio-demographic and clinical variables

Variable	n	Mean BAS ± SD	P-value
Gender: Male / Female	50/110	64.3 ± 14.2 / 76.4 ± 15.6	<0.001
Occupation: Farming/Daily wage vs. Other	98/62	75.8 ± 16.1 / 67.2 ± 14.3	0.002
Education: <10th / ≥10th	102/58	76.5 ± 15.4 / 65.9 ± 14.7	<0.001
Illness duration: <5 / ≥5 years	58/102	65.1 ± 13.8 / 76.9 ± 15.9	<0.001
Family type: Nuclear / Joint	98/62	75.2 ± 16.3 / 68.4 ± 14.1	0.008

Table 2: Severity distribution of caregiver burden (n=160)

Burden Category	n (%)	Mean BAS Score ± SD
Mild (<40)	15 (9.4)	34.2 ± 3.8
Moderate (40–80)	84 (52.5)	62.7 ± 9.4
Severe (>80)	61 (38.1)	88.5 ± 6.2
Moderate-to-Severe	145 (71.3)	72.6 ± 15.8

Table 3: Domain-wise mean scores on Burden Assessment Schedule (BAS)

Domain	Mean Score ± SD
Physical and mental health of the caregiver	19.4 ± 4.3
Caregiver's routine	17.8 ± 4.1
Support of the patient	14.2 ± 3.9
Taking responsibility	12.6 ± 3.5
Other relations	8.6 ± 2.7

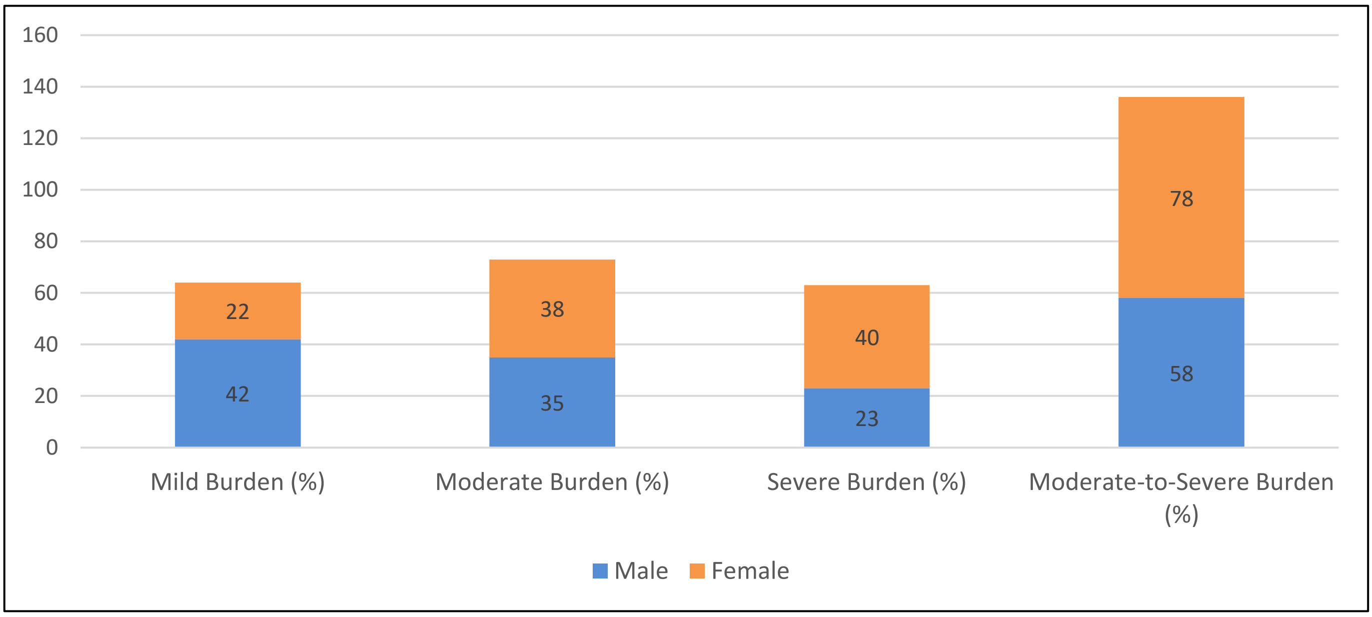

Figure 1: Gender-wise distribution of burden severity (Bar chart: Females show ~78% moderate-to-severe burden vs. ~58% in males, highlighting gender disparity.)

Figure 1 illustrates the marked gender difference in the severity of caregiver burden. While 58% of male caregivers experienced moderate-to-severe burden, the proportion was substantially higher among female caregivers at approximately 78%. The chart clearly demonstrates that female caregivers (predominantly mothers and wives) bear a disproportionately higher burden compared to males, supporting the finding that female gender is an independent predictor of increased caregiver burden in this rural setting.

Correlates: BAS score showed positive correlations with PANSS total (r=0.51, P<0.001) and illness duration (r=0.42, P<0.001). Multiple linear regression (adjusted R^2=0.49) confirmed independent predictors: female gender, low education/agricultural occupation, longer illness duration, higher PANSS score, and lower income (all P<0.05).

DISCUSSION

The present study documented a high level of caregiver burden among primary caregivers of patients with schizophrenia in the rural peri-urban areas of Sonipat and Jhajjar districts around Delhi-NCR. The mean BAS score of 72.6 ± 15.8 and the prevalence of moderate-to-severe burden (71.3%) are consistent with or slightly higher than the pooled mean BAS score of 71.39 reported in a recent meta-analysis of Indian studies on schizophrenia caregivers [3]. This similarity underscores the pervasive nature of caregiver burden in India, while the marginally elevated scores in our rural sample may reflect the additional stressors of agricultural livelihoods, seasonal income instability, and limited access to specialized mental health services compared to purely urban or tertiary care settings.

A notable finding was the significantly higher burden among female caregivers (mean BAS 76.4 vs. 64.3 in males, P<0.001), which aligns with multiple Indian studies attributing this disparity to traditional gender roles. Women, often mothers or wives, frequently shoulder dual responsibilities of household management, farming activities, and caregiving, leading to greater physical exhaustion and emotional strain [5,8]. In rural Haryana, where patriarchal norms remain strong and external support systems are minimal, female caregivers are particularly vulnerable to burnout and subsyndromal psychiatric morbidity.

Low education and agricultural/daily-wage occupation emerged as independent predictors of higher burden, consistent with earlier observations that lower socioeconomic status and livelihood disruptions amplify objective burden domains such as caregivers' routine and financial strain [6,14]. The strong positive correlation between patient symptom severity (PANSS total score) and caregiver burden (r=0.51, P<0.001) reinforces findings from rural South India, where patient disability was directly linked to increased family burden [5]. Similarly, longer illness duration (>5 years) was associated with greater burden, reflecting the cumulative effect of chronicity on family resources and coping capacity [7].

Domain-wise analysis revealed the highest burden in "physical and mental health of caregiver" and "caregiver's routine," which is expected in a rural agricultural context where caregiving interferes with essential farming and household duties. These findings mirror those reported in North Indian studies and a comparative study from Haryana showing higher BAS scores in schizophrenia caregivers compared to bipolar disorder [8,15]. Joint families offered modest protection (lower mean BAS scores), likely due to shared responsibilities—a cultural buffer frequently noted in Indian literature, though its effectiveness appears limited in the face of severe or prolonged illness [10].

The observed burden levels are comparable to those reported in other rural or semi-urban Indian settings, where severe burden has ranged from 38–80% depending on the population and tool used [7,16]. Proximity to Delhi-NCR provides some referral opportunities, yet the persistently high burden highlights ongoing treatment gaps, stigma, and inadequate integration of family support services within the District Mental Health Programme. Qualitative studies from North India further contextualize these quantitative findings by describing caregivers' experiences of social isolation, financial hardship, and emotional exhaustion [8].

Strengths of this study include its community-based sampling in true rural-peri-urban transitional areas (rather than hospital-only settings), use of a culturally validated and India-specific tool (BAS with high internal consistency), and comprehensive assessment of both socio-demographic and clinical correlates using standardized scales. The inclusion of PANSS for objective symptom severity adds robustness to the correlates identified.

Limitations must be acknowledged. The cross-sectional design precludes causal inferences between identified predictors and burden. Consecutive sampling from treatment-seeking families may overestimate burden by excluding caregivers of untreated or less severe cases. Reliance on self-report measures introduces the possibility of social desirability or recall bias, although anonymity and trained interviewers were employed to minimize this. Finally, the study did not assess positive aspects of caregiving or detailed coping strategies, which could provide a more balanced perspective.

In conclusion, the high caregiver burden documented in this study from rural areas around Delhi-NCR calls for urgent, multilevel interventions. Routine screening of caregivers using simple tools like BAS should be integrated into DMHP services. Gender-sensitive family psychoeducation programs, livelihood support (e.g., agricultural assistance or respite care), and community-based rehabilitation initiatives tailored to rural realities are essential. Strengthening linkages between primary health centers and tertiary facilities in the NCR region, along with awareness campaigns to reduce stigma, could significantly alleviate this hidden burden. Longitudinal studies evaluating the impact of such family-focused interventions, as well as research exploring resilience factors and positive caregiving aspects in similar settings, are strongly recommended to guide evidence-based policy under the National Mental Health Programme.

Conclusion

This study documents a substantial burden of caregiving for schizophrenia in rural areas around Delhi-NCR, influenced by gender, socioeconomic, and clinical factors. Integrating routine caregiver assessment, family psychoeducation, livelihood support, and gender-sensitive programs into District Mental Health Programme services is essential. Further longitudinal and intervention-based research in similar peri-urban rural settings is warranted.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability

Available from the corresponding author on reasonable request.

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