

CAREGIVER BURDEN AND ASSOCIATED SOCIO-DEMOGRAPHIC FACTORS AMONG FAMILY CAREGIVERS OF INDIVIDUALS WITH SEVERE MENTAL ILLNESS

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ABSTRACT

Background: Family caregivers are central to the care of individuals with severe psychiatric disorders, particularly in low-resource settings. The chronic and relapsing nature of these illnesses often imposes a significant burden on caregivers, impacting their emotional, physical, social, and financial well-being. **Aim:** This study aimed to assess the burden experienced by family caregivers of individuals with severe psychiatric disorders and examine its association with key socio-demographic variables. **Methodology:** A cross-sectional descriptive study was conducted at the Department of Psychiatry, ABVIMS & Dr. RML Hospital, New Delhi. A total of 100 caregivers were recruited through convenience sampling. Data were collected using a socio-demographic datasheet and the Family Burden Interview Schedule (FBIS), and inferential statistics (ANOVA, linear regression) were employed. **Results:** Caregivers reported moderate to high levels of burden, with the highest scores in the domains of mental health impact, routine disruption, and family interaction. The overall mean burden score was 15.9 ± 3.9 , indicating a considerable level of caregiver burden in the study sample. Linear regression analysis revealed that caregiver age, gender, educational level, employment status, and duration of caregiving were significantly associated with burden scores ($p < 0.05$). **Conclusion:** The findings highlight the pervasive burden faced by caregivers and underscore the need for caregiver-centred mental health policies and psychosocial interventions. Tailored support strategies based on socio-demographic risk factors are essential to reduce distress and improve care outcomes.

Keywords: Caregiver burden, psychiatric illness, schizophrenia, bipolar disorder, socio-demographic correlates, mental health services, family support.

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INTRODUCTION

Family caregivers play a crucial role in sustaining treatment adherence, ensuring

safety, and promoting recovery in individuals with severe mental illnesses such as

schizophrenia, bipolar disorder, and major psychosis. In India and similar Low Middle Income Countries, where mental health infrastructure is overstretched and underfunded, families are often the sole caregivers, filling critical service gaps (Kohn et al., 2004).

Caregiving under these conditions comes at a significant personal cost. Chronic caregiving is known to cause physical exhaustion, emotional fatigue, financial strain, and social isolation (Chadda, 2014). Caregivers frequently report experiencing symptoms of anxiety, depression, and burnout, a phenomenon now recognized as "caregiver burden" (Zarit et al., 1980). Despite these challenges, their needs remain largely unaddressed in routine psychiatric care.

This study aims to investigate the perceived burden defined here as the objective and subjective demands placed on caregivers by the caregiving role (Pearlin et al., 1990) experienced by caregivers of patients with severe psychiatric illnesses, and to explore how this burden correlates with socio-demographic variables. The study draws on Pearlin's Stress Process Model (1990) as an organizing framework, which posits that caregiver burden emerges through an interplay of stressors, mediating conditions, and socio-demographic factors. This framework provides a conceptual basis for predicting which caregiver subgroups may be at greatest risk of high burden and in need of structured support.

Numerous studies have highlighted the multidimensional impact of caregiving in psychiatric settings. A seminal study by Pai and Kapur (1981) developed the Family Burden Interview Schedule (FBIS), which is widely used in India to quantify caregiver burden. Their findings revealed substantial burden in economic, social, and emotional domains, particularly when caregivers lacked formal support systems. Chakrabarti (2013)

emphasized that caregiver burden is influenced by contextual factors such as poverty, chronic illness, stigma, and cultural beliefs. Female caregivers were found to be more adversely affected in terms of emotional and physical health outcomes.

Reinares et al. (2006) examined what matters most to bipolar patients' caregivers, identifying helplessness, unpredictability of symptoms, and unmet information needs as primary sources of distress. Separately, a systematic review and meta-analysis by Yesufu-Udechuku et al. (2015) found that psychoeducational interventions significantly reduced caregiver burden across psychiatric diagnoses, underscoring the importance of early caregiver support. Caregivers of individuals with schizophrenia face distinct challenges including managing disorganized behaviour and social withdrawal, while those caring for individuals with bipolar disorder report difficulties coping with mood unpredictability (Saunders, 2003; Perlick et al., 2006).

Recent studies (Rammohan et al., 2002) conducted in India have demonstrated that caregivers from rural or low-SES backgrounds experience significantly higher levels of burden and have limited access to information and mental health services. This highlights the necessity for context-sensitive assessments and policy-oriented research focused on caregiver experiences.

The aim of this study was to assess the level of burden experienced by family caregivers of individuals with severe psychiatric disorders and to examine the association between caregiver burden and selected socio-demographic variables.

MATERIALS AND METHODS

Study Design and Setting

The present study adopted a descriptive cross-sectional research design to assess the burden experienced by family caregivers of

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individuals diagnosed with severe psychiatric disorders. The study was conducted at the Outpatient Department of Psychiatry at the Centre of Excellence in Mental Health, Atal Bihari Vajpayee Institute of Medical Sciences (ABVIMS), and Dr. Ram Manohar Lohia (RML) Hospital in New Delhi. The data collection period spanned from March to May 2024.

The study population consisted of primary caregivers of individuals undergoing psychiatric treatment for severe mental illnesses. A total of 100 caregivers were selected for participation using a convenience sampling method, based on their availability and willingness to participate during the data collection period. All participants were caregivers of individuals diagnosed with severe psychiatric conditions, including schizophrenia, bipolar affective disorder, and other major psychotic disorders as defined by ICD-10 criteria (ICD-10 was retained because ABVIMS & Dr. RML Hospital had not formally transitioned to ICD-11 at the time of data collection in 2024; the diagnostic categories for the conditions studied remain substantively unchanged between the two editions).

To be eligible for the study, participants had to meet the following inclusion criteria: (1) the caregiver must be 18 years of age or older, (2) must be an unpaid primary caregiver who has been providing care for a minimum of six months, and (3) must be willing to provide informed consent for participation. Caregivers were excluded from the study if they were employed as paid caregivers or institutional staff members, or if they had a diagnosed psychiatric illness, as these factors could independently influence burden scores and skew the findings.

Tools

Socio-Demographic Data Sheet: This semi-structured datasheet was developed by the researchers to collect relevant background information about the caregiver. It included

variables such as age, gender, education level, occupation, relationship to the patient, duration of caregiving, marital status, and living arrangement with the patient.

Family Burden Interview Schedule (FBIS):

Developed by Pai and Kapur (1981), the FBIS is a standardized 24-item interview schedule designed specifically for Indian settings. It assesses six key domains of family burden: (1) financial burden, (2) disruption of daily routine, (3) disruption of family leisure, (4) disruption of family interactions, (5) effect on physical health of the caregiver, and (6) effect on mental health of the caregiver. Each item is rated on a 0–2 scale, yielding domain-specific scores and a total burden score ranging from 0 to 48. In the present sample, the FBIS demonstrated good internal consistency (Cronbach's $\alpha = 0.81$), consistent with its established reliability in Indian populations.

Data Collection Procedure

Prior to data collection, ethical clearance was obtained from the Institutional Ethics Committee of ABVIMS & Dr. RML Hospital. Participants were approached in the outpatient waiting areas and provided with comprehensive information regarding the study's objectives, assurances of confidentiality, and the voluntary nature of participation. After obtaining written informed consent, data were collected through face-to-face interviews conducted in either Hindi or English, based on the participant's preference. The interviews were conducted by trained psychiatric social workers with experience in qualitative and quantitative mental health assessments. Each interview lasted approximately 30 to 45 minutes and was conducted in a private setting to ensure confidentiality and encourage open communication.

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Statistical Analysis

The data collected were entered into and analyzed using IBM SPSS Statistics for Windows, Version 26.0. Descriptive statistics, including means, standard deviations, frequencies, and percentages, were used to summarize the socio-demographic profiles of the caregivers and the levels of burden across the FBIS domains. Inferential statistics were employed to identify associations between caregiver burden scores and socio-demographic variables.

RESULTS

Table 1. Socio-Demographic Characteristics of Caregivers (N=100)

Variable	Category	n	%
Gender	Male	56	56.0
	Female	44	44.0
Educational Status	Graduate and Above	38	38.0
	Less than Graduate	62	62.0
Employment Status	Employed	45	45.0
	Unemployed	55	55.0
Relationship to Patient	Parent	38	38.0
	Spouse	26	26.0
	Other Relative	36	36.0
Duration of Caregiving	<1 Year	22	22.0
	1-3 Years	39	39.0
	>3 Years	39	39.0
Age (years)	Mean $\pm$ SD	39.3 $\pm$ 11.8	-

Table-1: Presents the socio-demographic characteristics of the caregivers. The mean age of the caregivers was 39.3 years (SD = 11.8). Male caregivers constituted 56% of the sample, while females accounted for 44%. Most caregivers had less than graduate-level education (62%), and more than half were unemployed (55%). Parents represented the largest caregiving group (38%), followed by spouses (26%) and other relatives (36%). Regarding caregiving duration, 78% of participants had been providing care for more than one year, indicating the long-term nature of caregiving responsibilities.

Table-2: Family Burden Interview Schedule (FBIS) Scores Among Caregivers (N = 100)

FBIS Domain	Mean $\pm$ SD
Financial Burden	2.6 $\pm$ 0.8
Disruption of Family Routine	2.8 $\pm$ 0.7
Disruption of Family Leisure	2.5 $\pm$ 0.9
Disruption of Family Interaction	2.7 $\pm$ 0.8
Effect on Physical Health	2.2 $\pm$ 0.9
Effect on Mental Health	3.1 $\pm$ 0.8
Total Burden Score	15.9 $\pm$ 3.9

Table-2: Presents the burden experienced by caregivers across various domains of the Family Burden Interview Schedule (FBIS). The highest burden was observed in the mental health domain (M = 3.1, SD = 0.8), indicating substantial psychological distress among caregivers. This was followed by disruption of family routine (M=2.8, SD=0.7) and disruption of family interaction (M=2.7, SD =0.8), suggesting that caregiving responsibilities considerably affected daily functioning and family relationships. Financial burden (M=2.6, SD=0.8) and disruption of leisure activities (M=2.5, SD=0.9) were also notable. The impact on physical health showed comparatively lower scores (M = 2.2, SD = 0.9). The overall mean burden score was 15.9 (SD = 3.9), indicating a considerable level of caregiver burden within the study sample.

Table-3: Multiple Linear Regression Analysis Predicting Caregiver Burden (N = 100).

Predictor	B	β	95% CI	p
Age (years)	0.12	0.28	0.02-0.22	.021*
Gender (Male)	1.10	0.26	0.06-2.14	.038*
Educational Level	-0.96	-0.27	-1.82 to -0.10	.031*
Employment (Employed)	1.23	0.31	0.26-2.20	.015*
Duration of Caregiving	1.34	0.34	0.39-2.29†	.007*
Relationship to Patient	0.48	0.12	-0.12-1.08	.114

$R^2 = .29$, Adjusted $R^2 = .24$, $F = 5.82$, $p < .001$.

Table-3: Presents the results of the multiple linear regression analysis examining socio-demographic predictors of caregiver burden. The overall model was statistically significant ($F=5.82$, $p<.001$) and explained 29% of the variance in caregiver burden scores ($R^2 = .29$; Adjusted $R^2=.24$). Older age ($\hat{\alpha}=.28$, $p=.021$), male gender ($\hat{\alpha}=.26$, $p=.038$), employment ($\hat{\alpha}=.31$, $p=.015$), and longer duration of caregiving ($\hat{\alpha}=.34$, $p=.007$) were significantly associated with higher caregiver burden. In contrast, higher educational attainment was associated with lower caregiver burden ($\hat{\alpha}=-.27$, $p=.031$). Relationship to the patient did not significantly

predict caregiver burden ($p = .114$).

DISCUSSION

The present study offers valuable insights into the challenges faced by family caregivers of individuals with severe psychiatric disorders, based on a sample of 100 caregivers. The findings indicate that caregiving for individuals with chronic psychiatric conditions, such as schizophrenia and bipolar disorder, is associated with significant psychosocial stress, particularly in the areas of mental health impact, disruption of daily routines, and family interactions.

The overall mean burden score was 15.9 ± 3.9 , indicating a considerable level of caregiver burden. The highest burden was reported in the domain of mental health impact, highlighting the emotional toll on caregivers. These findings align with earlier literature that emphasizes the psychological challenges faced by caregivers, including anxiety, depressive symptoms, and emotional exhaustion (Kate et al., 2013; Grover et al., 2012). Recent systematic reviews continue to demonstrate substantial psychological burden, emotional distress, and reduced quality of life among caregivers of individuals with severe mental illness (Tesfaye et al., 2025; Grover et al., 2025).

Significant disruptions were also reported in daily routines ($M=2.8 \pm 0.7$) and family interactions ($M=2.7 \pm 0.8$), emphasizing how caregiving responsibilities interfere with daily functioning and family cohesion. These disruptions are consistent with recent evidence demonstrating that caregiving responsibilities frequently interfere with family functioning, social participation, and daily routines among caregivers of individuals with mental illness (Leta et al., 2025; Deng et al., 2026).

Financial burden ($M=2.6 \pm 0.8$) emerged as another significant area of concern. Financial burden remains a major component of

caregiver burden, particularly in resource-constrained settings where caregivers frequently bear treatment costs and indirect productivity losses (Tesfaye et al., 2025; Leta et al., 2025). Despite the presence of government subsidies and hospital-based support systems, out-of-pocket expenditures remain high, especially in long-term psychiatric care. These financial concerns exacerbate stress and contribute to a negative caregiving experience.

Disruption in leisure activities ($M=2.5 \pm 0.9$) and the impact on physical health ($M=2.2 \pm 0.9$) were relatively lower, though still present. Recent evidence indicates that caregiver burden is associated with poorer physical health, psychological distress, and reduced quality of life among family caregivers (Esmaeeli et al., 2025; Gagiü et al., 2025). Long-term caregiving responsibilities may adversely affect caregivers' physical and psychological well-being, increasing stress, fatigue, and health-related challenges (Deng et al., 2026; Toleuov et al., 2025).

The study also explored associations between caregiver burden and socio-demographic factors. The association between older age and higher burden is consistent with recent evidence indicating that deteriorating caregiver health and prolonged caregiving responsibilities contribute to increased caregiver stress and burden (Deng et al., 2026).

Interestingly, male caregivers reported significantly higher burden ($B=1.10$, $p=0.038$). This finding challenges the traditional assumption that female caregivers inherently bear a higher burden. Instead, it resonates with recent Indian studies indicating that employed males may experience significant role conflict between being primary financial providers and taking on caregiving duties, leading to heightened psychological distress (Mathias et al., 2019).

Higher educational status was associated with

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lower burden ($B = -0.96$, $p = 0.031$). Educational attainment may facilitate access to health information, coping resources, and support systems, which may contribute to lower levels of caregiver burden (Esmaeeli et al., 2025). The duration of caregiving showed a significant positive association with burden ($B = 1.34$, $p = 0.007$). The association between longer caregiving duration and higher burden is consistent with recent studies demonstrating that prolonged caregiving demands contribute to increased stress and caregiver burden over time (Care Tasks and Caregiver Burden Among Family Caregivers, 2025).

Recent evidence suggests that caregiver burden among family caregivers of individuals with mental illness remains a significant global public health concern and is consistently associated with adverse psychosocial outcomes, psychological distress, and reduced quality of life (Tsfaye et al., 2025). Furthermore, caregiver burden has been shown to negatively influence overall life satisfaction and well-being among caregivers of individuals with schizophrenia and other severe mental illnesses (Esmaeeli et al., 2025). Importantly, emerging evidence indicates that structured psychosocial interventions, caregiver support programmes, psychoeducation, and community-based support services can effectively reduce caregiver burden, enhance coping capacities, and improve the overall well-being of both caregivers and care recipients (Sevillano-Garayoa et al., 2025). These findings highlight the need for integrating caregiver-focused interventions into routine mental healthcare services to promote sustainable caregiving and improve long-term treatment outcomes.

CONCLUSION

The present study highlights that the family caregivers of individuals with severe psychiatric disorders experience a moderate

to high level of burden, significantly impacting their mental health, daily routines, and family dynamics. Socio-demographic variables such as age, gender, educational status, employment, and duration of caregiving were found to significantly influence the level of burden experienced. Older age, male gender, employment, and longer caregiving duration were associated with higher burden, while higher educational attainment appeared to be a protective factor. These findings are consistent with the socio-demographic branch of Pearlin's Stress Process Model, which frames caregiver burden as an outcome of accumulated stressors moderated by personal and social resources. The results underscore the complex and multifactorial nature of caregiving burden in mental illness and emphasise the need for comprehensive, family-centred support mechanisms within the mental healthcare system.

IMPLICATION

Need for Caregiver-Centred Interventions: The significant burden identified across various domains highlights the urgent need for targeted psychosocial interventions, including counselling, psychoeducation, and stress management for caregivers. **Policy Development for Family Support:** The results advocate for health policies that formally recognise and support family caregivers through services like respite care, financial aid, and inclusion in treatment planning. **Diagnosis-Specific Support Programmes:** Given that schizophrenia and bipolar disorder impose distinct types of burden, mental health services should develop tailored caregiver support interventions specific to each diagnostic group. **Attention to High-Risk Caregiver Subgroups:** Older, male, employed, and long-duration caregivers represent identifiable high-risk subgroups. Routine burden screening in outpatient settings could facilitate early referral to support services for

these groups.

LIMITATIONS

Cross-Sectional Design: The study's cross-sectional nature restricts the ability to establish causal relationships between socio-demographic variables and caregiver burden over time. Longitudinal research is needed to understand how burden evolves across the caregiving trajectory. **Single-Centre Urban Sample:** As data were collected from one urban tertiary hospital, the findings may not be generalizable to rural populations, community settings, or caregivers who do not access formal psychiatric services. **OPD-based recruitment** may over-represent caregivers experiencing higher burden. **Convenience Sampling:** The use of convenience sampling introduces potential selection bias. Caregivers who attended the OPD during the data collection window may differ systematically from those who did not.

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