



CAREGIVER BURDEN AND ITS ASSOCIATION WITH UNMET NEEDS IN SEVERE MENTAL ILLNESS: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Severe mental illness (SMI) is a chronic and disabling condition that places substantial demands not only on patients but also on their caregivers. In low- and middle-income countries like India, families serve as the primary source of long-term care. Persistent unmet needs among patients may exacerbate caregiver burden, negatively affecting both caregiver well-being and patient outcomes. However, evidence examining the relationship between caregiver burden and unmet needs in SMI remains limited.

Method: This hospital-based cross-sectional study was conducted among 150 patients with severe mental illness attending a tertiary care psychiatry outpatient service and their primary caregivers. Patients aged 18–75 years with a minimum illness duration of two years and a Global Assessment of Functioning score of ≤ 70 were included. Unmet needs were assessed using the Camberwell Assessment of Needs – Research Version (CAN-R), and caregiver burden was evaluated using the Burden Assessment Schedule (BAS). Sociodemographic and clinical variables of patients and caregivers were recorded. Associations between unmet needs and caregiver burden were examined using non-parametric tests and Spearman's correlation.

Result: Caregivers experienced a moderate to high level of burden, with a mean BAS score of 26.74 ± 6.33 . A significant positive correlation was observed between total unmet needs and caregiver burden ($p < 0.05$). Higher caregiver burden was also associated with increased cost of medication and greater number of inpatient admissions. Social and financial unmet needs-particularly welfare benefits, money, household management, and daytime activities-were more strongly linked to caregiver burden than clinical needs.

Conclusion: Caregiver burden is closely associated with unmet needs among patients with severe mental illness. Addressing patient needs, particularly in social and financial domains, may reduce caregiver burden and improve overall treatment outcomes. Integrating caregiver-focused interventions and strengthening psychosocial support services are essential components of comprehensive mental health care.

Keywords: Severe Mental Illness; Caregiver Burden; Unmet Needs; Camberwell Assessment of Needs; Burden Assessment Schedule.

INTRODUCTION

Severe mental illness (SMI), including schizophrenia and affective psychoses, is a major contributor to global disability and long-term functional impairment.^[1] In India, the burden of care for individuals with SMI largely rests on family members due to limited community-based mental health services and inadequate social welfare support.^[2] Caregivers are often responsible for supervising treatment, managing behavioural disturbances, providing financial support, and assisting with daily living activities over prolonged periods.

While clinical outcomes such as symptom reduction and relapse prevention are important, they do not adequately capture the lived experiences of patients and caregivers. The concept of *unmet needs* has therefore emerged as a critical outcome measure in psychiatric care, reflecting gaps between patient requirements and available services.^[3] Unmet needs in domains such as finances, welfare benefits, social relationships, and daily activities are common in individuals with SMI and are known to adversely affect quality of life and service satisfaction.^[4,5]

Caregiving in SMI is associated with significant emotional, physical, and financial strain. Caregiver burden has been defined as the psychological distress and practical difficulties experienced while caring for a mentally ill relative.^[6] Studies have shown that higher caregiver burden is linked to poorer caregiver mental health, reduced coping capacity, and compromised patient care.^[7] Importantly, unmet patient needs may intensify caregiver burden by increasing caregiving demands and stress.^[8]

International studies have demonstrated a strong association between unmet needs and caregiver burden, particularly when social and functional needs remain unaddressed.^[9] Indian studies in this area are scarce, despite the central role of family caregivers in mental health care delivery.^[10]

Understanding the relationship between caregiver burden and unmet needs is crucial for developing holistic, family-oriented mental health interventions.

AIMS AND OBJECTIVES

The present study aims to assess the level of caregiver burden among caregivers of patients with severe mental illness attending a tertiary care centre and to examine its association with the unmet needs of these patients. It also seeks to identify the relationship between caregiver burden and selected Sociodemographic and clinical variables of patients and caregivers, in order to better understand factors contributing to unmet needs and increased caregiver strain in severe mental illness.

MATERIALS AND METHODS

Study Design

A hospital-based cross-sectional study was conducted over a one-year period from March 16, 2016 to March 15, 2017, after obtaining approval from the Institutional and University Ethics Committees. The study was carried out at the Department of Psychiatry, Dr. Somervell Memorial CSI Medical College, Karakonam, Kerala, a 550-bed tertiary care teaching hospital providing outpatient, inpatient, and 24-hour emergency psychiatric services. Caregivers of patients with severe mental illness attending the psychiatry outpatient department were consecutively assessed, and those fulfilling the inclusion criteria were recruited after obtaining informed consent. Patients were evaluated and managed by psychiatry trainees and consultant psychiatrists as part of routine care, with clinical and demographic details documented in hospital records.

Inclusion and Exclusion Criteria

The study included patients aged 18–75 years of either gender diagnosed with severe mental illness as per ICD-10 criteria, comprising affective and non-affective functional psychotic disorders such as schizophrenia, schizotypal disorder, persistent and induced delusional disorders, schizoaffective disorder, other and unspecified non-organic psychoses, manic episode, bipolar affective disorder, and severe depressive episodes with psychotic symptoms. Patients were required to have a minimum

duration of treatment of two years and a Global Assessment of Functioning score of 70 or less, indicating significant functional impairment. Only patients with an identifiable primary caregiver who consented to participate were included. Patients or caregivers who did not provide informed consent, patients with comorbid organic brain syndromes, and those with significant physical disabilities were excluded from the study.

Sample Size Calculation

Considering the prevalence of unmet needs to be ranging from 25% to 85.4% (55, 29, 101, 31) in literature, alpha error and power were fixed at 0.05 and 80% respectively, we have estimated the prevalence of unmet needs to be 40% with a precision of 8%, the sample size calculated was 150.

The formula employed was

$$SS = Z^2 PQ/D^2, SS = 4*0.4*0.6 / (0.08)^2 = 150.$$

Data Collection Tools

Data were collected using standardized and validated instruments. A semi-structured proforma was used to record the socio-demographic and clinical details of patients and caregivers, including age, gender, marital status, family type, duration of illness, history of suicide attempts, inpatient admissions, substance use, treatment details, medication side effects, cost of treatment, and availability of support during emergencies, along with caregiver characteristics such as the relationship to the patient, gender, literacy, and time spent in caregiving. Psychiatric diagnoses and comorbidities were confirmed using the Mini International Neuropsychiatric Interview (MINI) version 5.0.0 based on ICD-10 criteria. The unmet needs of patients were assessed using the Camberwell Assessment of Needs – Research Version (CAN-R), which evaluates met and unmet needs across 22 clinical and social domains. Caregiver burden was measured using the Burden Assessment Schedule (BAS), a 20-item interviewer-rated scale assessing subjective burden across wellbeing, relationships, social functioning, and perceived illness severity. Disability related to mental illness was evaluated using the Indian Disability Evaluation and Assessment Scale (IDEAS), an instrument approved by the Government of India to quantify functional disability in persons with severe mental illness.

Data Collection Procedure

Written informed consent was obtained from all patients and their primary caregivers prior to participation in the study. Data collection was carried out in a private setting, ensuring confidentiality and ethical standards throughout the process. The principal investigator personally interviewed patients with severe mental illness and their caregivers attending the psychiatry outpatient department, and collected information on socio-demographic and clinical variables, disability status, unmet needs, and caregiver burden using standardized assessment tools. All procedures were conducted in accordance with institutional ethical guidelines.

Statistical Analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS), version 20.0. Descriptive statistics were used to summarise socio-demographic and clinical characteristics of patients and caregivers. As the distribution of unmet needs scores was non-normal, non-parametric statistical tests were applied. The Mann–Whitney U test and the Kruskal–Wallis test were used to examine associations between categorical independent variables and unmet needs. Spearman’s rank correlation coefficient was employed to assess relationships between continuous variables and outcome measures, including unmet needs and caregiver burden.

RESULTS

Variable	Category	n (%)
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Gender	Male	67 (45.0)
	Female	83 (55.0)
Marital status	Married	78 (52.0)
	Single	37 (25.0)
	Widowed/Separated/Divorced	35 (23.0)
Family type	Nuclear	130 (87.0)
	Non-nuclear	20 (13.0)
Locality	Rural	141 (94.0)
	Urban	9 (6.0)

Table 1. Socio-demographic Profile of Patients with Severe Mental Illness (N = 150)

Table 1 describes the socio-demographic characteristics of patients with severe mental illness, showing a predominance of females, married individuals, nuclear families, and rural residence.

Variable	Category	n (%)
Diagnosis	Schizophrenia	55 (36.7)
	Bipolar affective disorder	54 (36.0)
	Schizoaffective disorder	13 (8.7)
	Unspecified psychosis	25 (16.7)
	Severe depressive disorder with psychosis	3 (2.0)
History of violent behaviour	Present	109 (72.7)
Substance use	Present	23 (15.3)
Medication side effects	Present	85 (56.7)

Table 2. Clinical Profile of Patients with Severe Mental Illness (N = 150)

Table 2 outlines the clinical characteristics of patients, with schizophrenia and bipolar affective disorder being the most common diagnoses and a high prevalence of violent behaviour and medication side effects.

Variable	Category	n (%)
Gender	Male	46 (30.7)
	Female	104 (69.3)
Relationship	Spouse	53 (35.3)
	Mother	39 (26.0)
	Others	58 (38.7)
Marital status	Married	129 (86.0)
Literacy	Illiterate	39 (26.0)
	Literate	111 (74.0)

Table 3. Caregiver Socio-demographic Characteristics (N = 150)

Table 3 presents caregiver characteristics, indicating that caregiving responsibility was predominantly borne by married female relatives, most commonly spouses and mothers.

Variable	Mean	SD
Total BAS score	26.74	6.34

Table 4. Mean Caregiver Burden Score (BAS) among Caregivers

Table 4 shows a moderate to high level of caregiver burden among caregivers of patients with severe mental illness.

Type of Need	Mean	SD
Total needs	5.35	2.89
Met needs	3.06	1.59

Unmet needs	2.29	1.99
Table 5. Distribution of Total, Met and Unmet Needs (CAN-R Scores)		

Table 5 illustrates that a substantial proportion of patient needs remained unmet despite ongoing psychiatric care.

Domain	Unmet needs n (%)
Welfare benefits	86 (57.3)
Money	52 (34.7)
Looking after home	31 (20.7)
Daytime activities	29 (19.3)
Psychotic symptoms	24 (16.0)
Intimate relationships	19 (12.7)
Table 6. Domain-wise Distribution of Major Unmet Needs (CAN-R)	

Table 6 highlights that social and financial domains constituted the most frequent areas of unmet needs among patients.

Variable	Spearman's ρ	p-value
Total caregiver burden score	0.175	0.032
Table 7. Association between Unmet Needs and Caregiver Burden		

Table 7 demonstrates a statistically significant positive correlation between caregiver burden and total unmet needs.

Variable	Spearman's ρ	p-value
Cost of medication	0.182	0.026
Number of inpatient admissions	-0.182	0.025
Table 8. Correlation of Unmet Needs with Selected Clinical and Treatment Variables		

Table 8 shows that higher treatment costs and increased inpatient admissions were significantly associated with greater unmet needs

DISCUSSION

The present study examined caregiver burden and its association with unmet needs among patients with severe mental illness (SMI) attending a tertiary care centre. The findings demonstrate a substantial level of caregiver burden and a significant burden of unmet needs, particularly in social and financial domains, with a clear positive association between the two.

In this study, the mean caregiver burden score was 26.74, indicating a moderate to high burden. This finding is consistent with earlier Indian studies using the Burden Assessment Schedule, which have reported considerable caregiver burden among families caring for individuals with schizophrenia and other severe mental illnesses.^[11–13] Similar levels of burden have also been documented in international studies, highlighting caregiving as a chronic stressor associated with emotional, physical, and financial strain.^[7,9] The high burden observed may be attributed to the chronic course of illness, functional impairment, behavioural disturbances, and lack of adequate community-based mental health services in low- and middle-income countries such as India.

The mean total number of needs in the present study was 5.35, with unmet needs accounting for a substantial proportion (mean unmet needs = 2.29). These findings are comparable to Western studies using the Camberwell Assessment of Needs (CAN), which report mean total needs ranging from 5.3 to 7.9.^[4,5] However, Indian studies have often reported higher total and unmet needs, reflecting

disparities in service availability and social welfare support.^[10,14] The persistence of unmet needs despite ongoing treatment underscores gaps in comprehensive care beyond symptom control. Social and financial domains-particularly welfare benefits, financial difficulties, household management, and daytime activities-were the most frequently reported unmet needs. This pattern closely mirrors findings from Indian studies, where lack of awareness of government welfare schemes and financial hardship have been identified as major unmet need areas.^[10,14,15] In contrast, studies from high-income countries more commonly report unmet needs related to employment, social relationships, and meaningful daytime activities.^[5,16,17] These differences emphasize the influence of socioeconomic context and health system structure on the nature of unmet needs.

A key finding of this study was the significant positive correlation between caregiver burden and unmet needs. Similar associations have been reported by Ochoa et al. and Siegel et al., who demonstrated that higher unmet patient needs are associated with increased caregiver stress and burden.^[9,8] Unmet needs may intensify caregiving demands, leading to emotional exhaustion, role strain, and reduced coping capacity among caregivers. Conversely, highly burdened caregivers may be less able to meet patient needs, suggesting a bidirectional relationship.

Among socio-demographic factors, married patients and those from nuclear families reported fewer unmet needs. Spousal support has been shown to play a protective role in meeting patient needs and reducing caregiver strain.^[18] Patients who were breadwinners prior to illness also reported fewer unmet needs, possibly reflecting greater family investment and perceived responsibility towards their care, as suggested in earlier Indian studies.^[14] Gender and locality were not significantly associated with unmet needs, consistent with some previous reports^[4] although other studies have shown mixed findings.^[16,19]

Clinical variables such as violent behaviour, substance use, and medication side effects were significantly associated with unmet needs. Violent behaviour has been linked to higher unmet needs, particularly in domains related to symptom management and psychosocial support.^[20] Substance use may further complicate treatment adherence and service utilization, thereby increasing unmet needs.^[21] Interestingly, patients with a family history of mental illness reported fewer unmet needs, possibly due to greater illness awareness, prior exposure to mental health services, and better caregiving skills within the family.^[22]

Female caregivers were associated with fewer unmet needs among patients, reflecting traditional caregiving roles and greater involvement in daily care activities.^[23] However, this may come at the cost of increased caregiver burden, as female caregivers consistently report higher levels of emotional and physical strain.^[23,24] The significant association between unmet needs and treatment-related factors such as the cost of medication and the number of inpatient admissions highlights the economic burden faced by families, which has been widely documented in Indian and international literature.^[25,26]

The findings reinforce the importance of addressing unmet needs as a central component of care in severe mental illness. Failure to do so not only compromises patient outcomes but also substantially increases caregiver burden, creating a cycle of stress and unmet care demands.

LIMITATIONS

The present study has certain limitations that should be considered while interpreting the findings. The cross-sectional design precludes causal inferences regarding the relationship between caregiver burden and unmet needs. The relatively small sample size and hospital-based setting may limit the generalizability of the results to community populations. Only selected socio-demographic and clinical variables were assessed, and important factors such as the severity of psychiatric symptoms, quality of life, coping strategies, and social support were not evaluated. Additionally, as most patients were clinically stable or in remission at the time of assessment, the extent of unmet needs and caregiver burden may have been underestimated.

CONCLUSION

The present study demonstrates that caregivers of patients with severe mental illness experience a considerable level of burden, which is significantly associated with the presence of unmet patient needs. Unmet needs were predominantly observed in social and financial domains, such as welfare benefits, financial support, household management, and daytime activities, highlighting gaps beyond routine clinical care. The close relationship between caregiver burden and unmet needs underscores the importance of comprehensive, family-oriented mental health services that address both patient requirements and caregiver well-being. Systematic needs assessment, enhanced psychoeducation, improved access to welfare benefits, and strengthened rehabilitation and caregiver support services may help reduce caregiver burden and improve overall outcomes in severe mental illness.

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