

A comparative study of family caregiver burden in schizophrenia and bipolar affective disorder

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ABSTRACT

Background: Caregiving for individuals with mental illness is one of the most difficult jobs among family members. The social and financial costs associated with mental illnesses are considerable for those who suffer from them, their families, and their communities. **Aim:** This study aimed to assess and compare the levels of burden experienced by family caregivers of individuals with schizophrenia and bipolar affective disorder. **Methodology:** A cross-sectional hospital-based descriptive research design was used in the study. The convenience sampling method was adopted to select 90 caregivers of severe psychiatric disorders, 45 individuals with Schizophrenia (Group-1) and 45 Bipolar Affective Disorders (Group-2). Participants were evaluated using a self-prepared socio-demographic datasheet and a family burden interview schedule (FBIS). **Results:** The mean age of the participants was in group-1 41.02 ± 11.63 years and group-2 35.97 ± 12.39 years. Results show that there was a significant difference level ($p < .001$) in various domains of FBIS among participants of both groups. **Conclusion:** Family caregivers take on several responsibilities when it comes to caring for people with mental illnesses when there is a lack of proper mental health infrastructure available.

Keywords: Carergiver burden, chronic mental illness, schizophrenia, bipolar disorders.

INTRODUCTION

Schizophrenia and bipolar affective disorder (BPAD) are chronic mental health conditions that require consistent and comprehensive care to manage symptoms and maintain functional outcomes. Significant impairment in emotional regulation, cognitive functioning, behavioural functioning, and disruptions in social adjustment. Over 90% of people with severe psychiatric problems reside with their family in India.^[1, 2]

The involvement of primary carers is essential in reducing hospitalisation rates for individuals with psychiatric illnesses, as a result of the deinstitutionalisation of treatment and care.^[3] Even with appropriate pharmacological and therapeutic treatment, people with severe psychiatric problems are not able to function normally or handle basic everyday tasks. It will take time for them to regain their higher mental

function as well as to get over this illness and restore their social functioning. Individuals with severe and persistent psychiatric problems frequently have low quality of life and impaired social functioning which create direct duties of family caregivers to handle individual's day to day basic requirements and other work; household, work, personal hygiene etc.^[1]

Schizophrenia and bipolar affective disorder (BPAD) are classified as Severe Mental Illnesses (SMI). SMI is defined as a mental, behavioural, or emotional issue that considerably limits or interferes with one or more major living activities and results in a significant functional impairment. Severe mental illnesses included schizophrenia, bipolar affective disorders, severe depression, and other psychotic diseases, according to the National Mental Survey of India. As to the

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survey, 0.8% of individuals currently deal with a severe mental illness, and roughly 1.9% have gone through one at some point in their lives.^[4] Caregiver difficulties were the perception of mental or physical stress that care providers experience. It is described as the tension brought on by tending to people who are unable to effectively perform daily tasks.^[5] These complex expressions aim to communicate the idea of the specialised role of caring for people with a variety of resources, strengths, and histories who are exhibiting symptoms unique to their disease.^[6] The theory was first proposed by Treudley in 1946, who asserted that giving care negatively impacts the caregiver's emotional health and manner of life.^[7] Financial, social, emotional, and physical resources are all used by carers to carry out their responsibilities.^[8]

A group of family members, known as primary caregivers, offers unpaid assistance to individuals with chronic illnesses. Those who attend to the care of individuals with severe psychological problems and long-term medical conditions are typically close relatives or family members.^[9] Care burden is classified as either objective or subjective. The phrase "objective burden" refers to the tangible consequences of providing care and encompasses the aspect of the job that is quantifiable or assessable by third parties.^[10,11] The emotional, psychological, and attitudes that carers have on their role providing care are referred to as "subjective burden."^[12-13] It focuses on how carers perceive their physical and emotional health to be impacted by their roles.

Dependency on primary carers develops in individuals with serious mental illness due to impairment of functioning and incapacity for decision making. A serious mental illness limits a person's ability to work and significantly impairs their ability to perform their tasks and functions. Family carers support 90% of patients with serious mental disorders on a daily basis both practically and emotionally.^[14]

Aim: This study aimed to assess and compare the levels of burden experienced by family caregivers of individuals with schizophrenia and bipolar affective disorder.

MATERIAL AND METHODS

After obtaining ethical approval from the Institutional Ethics Committee, the study

commenced in the Department of Psychiatry, Centre of Excellence in Mental Health, Dr. RML Hospital New Delhi. It was conducted following the timeline between 1st March 2024 to 31st May 2024. Family caregivers of individuals receiving treatment from this department constituted the study population. A total of 90 respondents were selected through convenient sampling as per the inclusion and exclusion criteria from the study. Caregivers of persons diagnosed with schizophrenia (Group-1) and bipolar affective disorder (Group-2) as per ICD-10^[15] criteria having a minimum duration of illness more than 2 years. Age 20-60 years and caring for individuals with the aforementioned psychiatric disorders for at least six months. Caregivers with severe physical or psychiatric illness or those caring for more than one individual were excluded, as were paid/professional caregivers. Data safety and confidentiality were maintained of caregivers throughout the study. All the participants were given written informed consent for the study. Participants were explained about the purpose and aim of the study. Individuals' and their caregivers' data were collected by using socio-demographic data sheet, Family Burden Interview Schedule.

The Family Burden Interview Schedule (FBIS)^[16] developed by Pai and Kapur was used to measure the carer burden among families of individuals with mental illness. It consists of 24 items categorised into six domains: financial burden, interruption of regular family activities, interruption of family leisure, interruption of family interaction, physical, and mental health. Three points are assigned to each item: 0 for no burden, 1 for moderate burden, and 2 for severe burden. This scale was developed in Indian setting. It is legitimate and dependable for use in clinical and research settings, with inter-rater reliability and coefficient coming in at 0.9 and 0.8, respectively. FBIS cut-off points are 0 for no burden, 1-16 get mild level burden, 17-32 represent moderate level of burden and 33-48 for severe level of burden.^[17]

Data analysis was performed using Statistical package of social science (SPSS) 25 version. Descriptive statistics in the form of frequency tables and, chi-squared test were used to assess the deference between various domains of demographics of the groups. t-test was applied to assess the level of burden among the groups.

RESULTS

Table 1: Socio-demographic details of participants (N=90)

Variable	Groups (n=45)		t/ χ^2	P
	1	2		
Age (Mean \pm SD)	41.02 \pm 11.63	35.97 \pm 12.39	1.631	.108
Education				
Primary	11	8	2.927	.711
Secondary	13	9		
Higher-secondary	8	8		
Graduate	5	9		
PG & Above	7	9		
Other	1	2		
Caregivers Relationship				
Parents	12	11	9.262	.550
Spouse	10	9		
Sibling	15	8		
Children	4	15		
Others	4	2		
Domicile				
Urban	34	34	.786	.675
Rural	6	8		
Semi-urban	5	3		
Occupation				
Unemployed	15	10	3.622	.728
Agriculture	5	6		
Daily Basis	9	12		
Homemaker	8	5		
Service	7	10		
Others	1	3		
Family Type				
Joint	22	29	2.217	.136
Nuclear	23	16		
Gender				
Male	34	31	.498	.480
Female	11	14		
Duration of Stay	29.82 \pm 17.61	31.91 \pm 14.67	1.596	.116
Duration of illness	5.66 \pm 5.37	3.78 \pm 2.86	1.35	.181

Table 1 shows the representation of socio-demographic details and found no significant difference between both the groups. Mean age of Group-1 caregivers was 41.02 ± 11.63 years, while for Group-2 it was 35.97 ± 12.39 years.

Table 2: Comparison between caregivers burden among both the groups (N=90)

Variables	Groups (Mean \pm SD)		t (df=88)	p
	1 (n=4)	2 (n=45)		
Financial	6.2 \pm 2.75	5.48 \pm 2.84	1.319	.190
Daily Routine	4.11 \pm 1.86	3.64 \pm 1.68	1.248	.215
Leisure	3.84 \pm 1.34	2.71 \pm 1.56	3.686	.001**
Family Interaction	4.84 \pm 1.58	3.42 \pm 1.95	3.790	.000**
Physical Health	2.02 \pm .83	.68 \pm .79	3.749	.000**
Mental Health	1.84 \pm 1.16	1.31 \pm .73	2.596	.001**
Subjective	1.55 \pm .50	1.00 \pm .56	4.933	.001**

Table 2 shows a significant difference in both groups on different subdomains of caregivers' burden: Family leisure activities, interaction pattern, physical health, mental health, subjective burden at $p < .001$ level.

Table 3 shows that, the burden experienced by two caregiver groups (Group 1 and Group 2, each with 45 participants) across multiple dimensions: financial burden, daily routine, family leisure, family interaction, physical health, mental health, and subjective burden.

Financial Burden: Both groups reported predominantly moderate financial burden (Group 1: 46.6%, Group 2: 44.4%). Severe burden was slightly higher in Group 1 (17.7%) than Group 2 (15.5%), while only Group 2 reported some participants with no burden (8.9%).

Impact on Daily Routine: The burden on daily routine was mostly moderate in both groups (Group 1: 51.1%, Group 2: 42.5%). Mild burden was more common in Group 2 (48.9%) than Group 1 (35.6%). Severe impact was notably higher in Group 1 (13.3%) compared to Group 2 (4.4%).

Family Leisure: Group 1 caregivers experienced more significant strain, with 66.7% reporting moderate and 20% reporting severe burden. In contrast, Group 2 had more respondents with mild or no burden (44.5%) and fewer reporting severe impact (4.4%).

Family Interaction: This domain revealed a stark contrast: 77.8% of Group 1 experienced

Table 3: Level of burden among the caregivers of both the groups (N=90)

Variables	Groups	
	Group-1(45)	Group-2 (45)
Financial Burden		
No Burden	0	4 (8.9)
Mild Burden	16(35.7)	14(31.2)
Moderate Burden	21(46.6)	20 (44.4)
Severe Burden	8(17.7)	7(15.5)
Daily Routine		
No Burden	0	2(4.4)
Mild Burden	16(35.6)	22(48.9)
Moderate Burden	23(51.1)	19(42.5)
Severe Burden	6(13.3)	2(4.4)
Family Leisure		
No Burden	0	6(13.3)
Mild Burden	6(13.3)	14(31.2)
Moderate Burden	30(66.7)	23(51.1)
Severe Burden	9(20)	2(4.4)
Family Interaction		
No Burden	0	3(6.6)
Mild Burden	6(13.3)	24(53.3)
Moderate Burden	35(77.8)	14(31.2)
Severe Burden	4(8.9)	4(8.9)
Physical Health Burden		
No Burden	2(4.4)	12(26.6)
Mild Burden	15(33.4)	16(35.6)
Moderate Burden	13(28.8)	16(35.6)
Severe Burden	15(33.4)	1(2.2)
Mental Health Burden		
No Burden	8(17.7)	5(11.1)
Mild Burden	10(22.2)	23(51.1)
Moderate Burden	14(31.2)	15(33.4)
Severe Burden	13(28.8)	2(2.2)
Subjective Burden		
No Burden	0	5(11.1)
Mild Burden	16(35.6)	9(20.0)
Moderate Burden	27(60.0)	24(53.3)
Severe Burden	2(2.2)	7(15.6)

moderate burden, compared to only 31.2% in Group 2. Meanwhile, 53.3% of Group 2 caregivers experienced only mild burden, suggesting better perceived support or coping.

Physical Health Burden: Group 1 faced higher physical health strain, with one-third (33.4%) reporting severe burden, compared to just 2.2% in Group 2. Conversely, 26.6% of Group 2 caregivers reported no physical burden, while this was negligible in Group 1 (4.4%).

Mental Health Burden: Mental health issues were more severe among Group 1, with 28.8% reporting severe burden, in contrast to only 2.2% in Group 2. Group 2 had a larger share experiencing only mild burden (51.1%) compared to Group 1 (22.2%).

Subjective Burden: Moderate burden was the most common in both groups, though slightly higher in Group 1 (60%) than Group 2 (53.3%). Severe subjective burden was higher in Group 2 (15.6%) than in Group 1 (2.2%), possibly indicating hidden stressors or unmet expectations.

DISCUSSION

Most of the caregivers were men, and the length of disease ranged from 2 to 32 years for patients with schizophrenia and from 2 to 30 years for those with bipolar disorder. The length of illness and the number of hospitalizations did not significantly differ between the two groups. The average age of caregivers for individuals with bipolar disorders was 35.97 ± 12.39 , with a range of 20 to 58, while the average age of caregivers of individuals with schizophrenia was 41.02 ± 11.63 , with a range of 25 to 60 years, as shown in Table 1. Participants in a cross-sectional survey with matched caregivers with a diagnosis of schizophrenia or bipolar disorders. The degree of care burden was shown to be unaffected by an individual's diagnosis of schizophrenia or bipolar disorders in a survey of 297 caregivers.^[18]

Group 1 caregivers generally reported higher levels of burden across most domains, particularly in physical and mental health, family interaction, and daily routines. Group 2, while still facing considerable burden, showed relatively better coping or support, especially in areas like physical health and family leisure. The differences may be attributed to variations in caregiving circumstances, availability of support systems, or differences in patient conditions.

The present study found that at various domains of FBIS significant at the ($P < 0.001$) level. As part of a broader cohort, two studies released

data on relatives of individuals with schizophrenia or bipolar illness. Due to the higher chronicity and severity of symptoms in both bipolar disorders, the investigations have raised the idea that, despite the belief that they are episodic, the costs of both diagnoses may be comparable. The impact of both diseases on caregivers was equal among the total 450 family members.^[19] Abbaslou et al. conducted a cross-sectional study with 100 caregivers of individuals with bipolar disorders or schizophrenia to evaluate caregiver burdens. For caregivers in the schizophrenia and bipolar disorders groups, they found a negative correlation ($P < 0.01$) between coping strategies and burden. Despite a direct correlation between burden and emotional-orientated, less helpful, and inefficient coping techniques, two different t-tests on samples showed that the burden among caregivers of individuals with bipolar disorders or schizophrenia was not different ($P < 0.24$).^[20]

This study found that psychiatric disorders made an impact on caregivers' difficulty levels. As per the global objective burden score, 72.9% of caregivers experienced psychosocial difficulties in the form of moderate to severe level burden. The present study also found similar overall burdens among the caregivers; researchers reported 75.1% and 73.6% for moderate to severe level burden.^[21,22] Although the overall effect size was trivial, the level of burden among the family members with schizophrenia was considerably higher than that in bipolar disorders at the ($P < 0.001$) level, which is consistent with previous findings.^[23,24] One study also revealed that family members of individuals who exhibit psychotic symptoms have more difficulties.^[25]

Caregivers of individuals with schizophrenia found inconsistency in burden, even though bipolar disorder individuals had longer durations of disease and treatment. One explanation for the discrepancy would be that while individuals with schizophrenia had long-lasting symptoms, the majority of individuals with bipolar disorders were in remission. Additionally, it can be because people with schizophrenia function at a lesser level than those with bipolar disorder. The objective burden is expected to be higher as the disease continues for a longer duration and the difficulties caregivers experienced increased in chronic conditions of illness.^[26] The pattern of

burden in different domains was nearly equal in both research groups, apart from the variation in global burden. In terms of external assistance, caregivers' routine, and other relationships, the two study groups' difficulties differ marginally; caregivers with schizophrenia experienced higher burdens than those with bipolar disorders.

Another important component of the caregivers' hardship was the disruption of their regular routines. Since schizophrenia is a chronic condition, it requires ongoing monitoring, and caregivers must always go with the patient to consultations. Caretakers consequently lack the time to attend to their activities and well-being. Their actions were extremely upsetting to the caregivers of people with schizophrenia and disrupted family activities and interactions.^[27]

CONCLUSION

In the absence of adequate mental health infrastructure, family caregivers continue to shoulder a significant burden. There is a need for structured interventions and caregiver support programs to reduce caregiver stress and improve coping strategies. In Indian family setting family caregivers are important source of taking care and support of Individuals with severe psychiatric illness. The caregiving duty places a significant care burden on family care givers, who require assistance from mental health specialists. In order to lessen the burden and assist in the development of good coping mechanisms, and required the implement appropriate interventions to reduce level of burden and enhance coping style.

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Ethical considerations: Taken

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