

# Burden of care in caregivers of patients with schizophrenia in Greater Noida, U.P., India

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## ABSTRACT

**Background:** Schizophrenia is a serious mental illness that causes major functional impairments, raises the risk of disability, and reduces life expectancy. It affects around 7 in 1000 people b/w the age of 15 and 35 years. Schizophrenia poses a great challenge not only for the patient but also for the people and the society around the patient. Family members who serve as informal primary carers may suffer personal expenses as a result of providing care for those who have major mental illnesses. One outcome that is regularly studied is the caregiver burden or the challenges encountered in providing care. **Aims:** Burden of care in caregivers of patients with schizophrenia in Greater Noida, U.P, India. **Methods:** This cross-sectional study was carried out at the School of medical sciences and Research, Sharda University. We enrolled 100 caregivers and it is assessed through the burden assessment scale. **Results:** Caregivers ranged in age from 20 to 85, with a mean age of 47 (SD=14.1). The male-to-female ratio was 1.7, with 63 men and 37 women present. The majority of the caregivers were parents (n=54), siblings (n=9), spouses (n=10), or their children (n=5). On the burden assessment scale, the severity of the burden was found on the basis of mild, moderate, severe, and very severe. **Conclusion:** It is important to understand the mental health of caregivers in order to develop an appropriate intervention to deal with their mental health problems. Therefore, this study highlighted the need for psychological interventions not only for the patients but also for caregivers.

**Keywords:** Burden, caregivers, schizophrenia

## Introduction

Schizophrenia is a serious mental illness that causes major functional impairments,<sup>[1]</sup> raises the risk of disability,<sup>[2]</sup> and reduces life expectancy. It affects around 7 in 1000 people between the ages of 15 and 35 years.<sup>[3]</sup> Schizophrenia poses a great challenge not only for the patient but also for the people and the society around the patient.<sup>[4]</sup> Family members, spouses,

friends, and other close relatives who serve as informal primary carers may suffer personal expenses as a result of providing care for those who have major mental illnesses.<sup>[5]</sup> Caregivers help with functional recovery, liaising with professionals, managing behaviour, daily living, finances, and emotional support.

One outcome that is regularly studied is caregiver burden or the challenges encountered in providing care.<sup>[6]</sup> Although there are various conceptualisations of caregiver load, objective and subjective burdens are the most frequently used terminologies.<sup>[7]</sup>

Studies have looked at how the social and demographic features in addition to clinical characteristics of patients

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along with their caregivers could affect care load and how these condition the quality of life of the latter in light of the negative effects of psychiatric family care.<sup>[8]</sup> It is challenging to offer compelling proof of the burden based on gender because of the feminisation of care.<sup>[9]</sup> However, in a patriarchal society, the mother typically completes the role out of moral obligation, making it challenging to balance employment and care. There is evidence that the caregivers' economic status and educational attainment, among other demographic factors, are related to the emotional and physical strain they bear. Social support may be protective<sup>[10]</sup> because it enables one to comprehend the compensatory and adjustment processes utilised to deal with caregiving challenges and to lessen the negative consequences that occur from providing someone with ongoing care.<sup>[11]</sup>

Another factor that affects the quality of caring is the emotional toll that providing care has on family members. This manifests as psychological distress that the individual perceives as exhausting or beyond his or her resources and posing a threat to their well-being.<sup>[12]</sup>

Because de-institutionalised schizophrenia patients embrace their family, it is crucial to examine the caregivers' stress levels, coping mechanisms, and psychological health because these factors have an impact on how well they are able to care for the patient with schizophrenia. Though Western studies have looked into the relationship between these variables, there is a particular dearth in the Indian studies during this field. This study assesses care load in carers of schizophrenia.

## Aims

Burden of care in caregivers of patients with schizophrenia in Greater Noida, U.P, India.

## Materials and Methods

### Study area

Out Patient Department of Psychiatry, Sharda Hospital, Greater Noida, Uttar Pradesh.

### Study population

All caregivers of the diagnosed cases of schizophrenia patients according to International Classification of Disease.<sup>[13]</sup>

### Study duration

June 2020 to July 2022.

### Study design

Cross-sectional analytical study.

### Inclusion criteria

- Written and informed consent from the caregiver of the patient.
- Patient diagnosed as schizophrenia consistent with

ICD-10/11 for a minimum period of 1 year.

- Age between 18 and 65 years of the primary caregiver.
- Availability of the caregiver for the assessment.
- The individual who is taking care of the patient for a minimum period of 1 year.
  - Primary caregiver is a first-degree relative (parents, siblings, children, spouse, or other close family members) who provides for the patient's requirements, supports them with everyday activities, monitors and treats their medical conditions, and gives the patient their undivided attention.

Exclusion criteria for the caregivers of diagnosed cases of schizophrenic patients as per ICD 10/11:

- Caregiver already having any established psychiatric disorder.
- Caregiver with co-morbid established substance use disorder.
- Caregiver with any chronic physical illness.

The following scale was used for data collection: "Burden assessment schedule" (BAS)

### 1. Burden assessment schedule

The Schizophrenia Research Foundation in Chennai, India, created the burden assessment schedule (BAS) to measure caregiver burden. The goal of the BAS is to evaluate the objective and subjective load that carers suffer. This 40-item instrument was created using a step-by-step ethnographic exploration methodology. This schedule has undergone reliability tests during its creation. Comparison with another standardised tool to measure burden has verified the criteria's validity.<sup>[14]</sup>

## Results

We enrolled 100 caregivers in our study. Table 1 describes the details of the caregivers of the patients. Caregivers ranged in age from 20 to 85, with a mean age of 47 [standard deviation (SD) = 14.1]. The male to female ratio was 1.7, with 63 men and 37 women present. There were 92 Hindu and 8 Muslim caregivers. A total of 98 respondents were married, and the average duration of marriage was 15.7 (SD = 10.8, range 1–43) years. The majority of the caregivers were qualified up to the intermediate level ( $n = 28$ ), followed by those who were graduates ( $n = 25$ ) and those who were educated up to the primary level ( $n = 22$ ). The majority of the respondents were unskilled workers ( $n = 62$ ), followed by skilled workers ( $n = 21$ ), and the rest were unemployed ( $n = 17$ ). The caregivers were related to the patients. The majority of the caregivers were parents ( $n = 54$ ), siblings ( $n = 9$ ), spouses ( $n = 10$ ), or their children ( $n = 5$ ).

Figure 1 describes the genderwise distribution of the caregivers.

Figure 2 describes the education of the carers.

Figure 3 describes the marital status.

Table 1: Characteristics of the carers of schizophrenic patients (n=100)		
Caregiver of the patient	Category	Frequency (%)
Age in years (Mean±SD)	47±14.1 Min-Max (20–85)	
Gender	Female	37 (37)
	Male	63 (63)
	Total	100 (100)
Religion	Hindu	92 (92)
	Muslim	8 (8)
	Total	100 (100)
	Marital Status	
Marital Status	Married	98 (98)
	Single	2 (2)
	Total	100 (100)
Education	Graduate	25 (25)
	High School	5 (5)
	Illiterate	8 (8)
	Intermediate	28 (28)
	Middle School	12 (12)
	Primary	22 (22)
	Total	100 (100)
Occupation	Skilled Employment	21 (21)
	Unemployment	17 (17)
	Unskilled Employment	62 (62)
	Total	100 (100)
Relationship with the patient	Brother	6 (6)
	Daughter	2 (2)
	Father	29 (29)
	Husband	24 (24)
	Mother	25 (25)
	Sister	1 (1)
	Son	3 (3)
	Wife	10 (10)
	Total	100 (100)
	Duration of marriage (in years)	15.7±10.8 Min-Max (1–43)

The mean score on burden assessment scale was 72.9 (SD = 20.8, range 38–117).

**Discussion**

Table 2 data shows that there is a burden on care givers which indicates that there is a need of proper evaluation of care givers as well. The purpose of this research was to identify the stress placed on carers of schizophrenic patients. Since this research was conducted at an urban tertiary care centre, its findings should not be extrapolated to the broader populace. In order to identify the factors that put carers of people with schizophrenia at risk for developing psychiatric co-morbidities, longitudinal studies are preferred over the current cross-sectional approach. Due to the limited time frame, only a small number of people were included in the sample.

On assessing the burden on the caregivers with respect to providing care to the patients, it was found that 23 caregivers had minimal burden, 29 had moderate burden, 21 had severe burden, and 5 had very severe burden [Table 3].

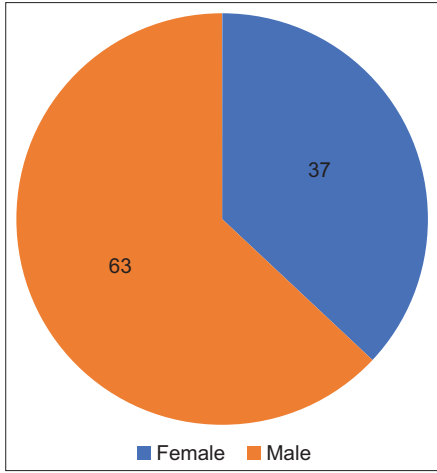


Figure 1: Gender-wise distribution of the caregiver

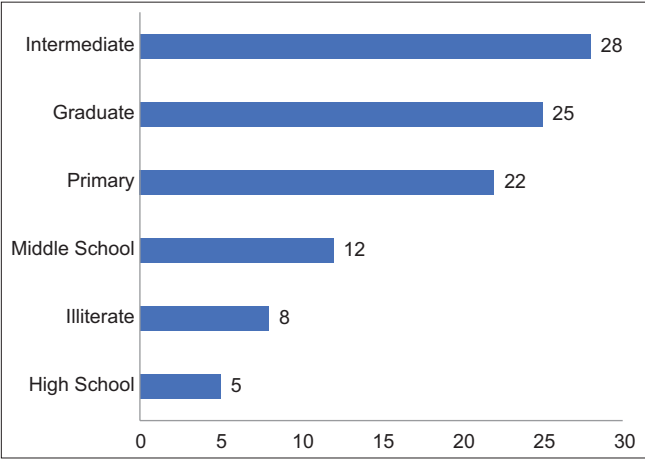


Figure 2: Education status of the caregiver

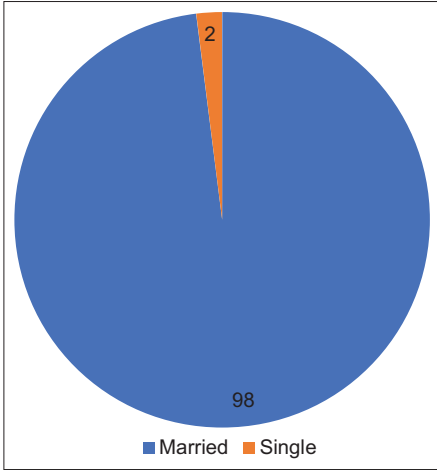


Figure 3: Marital status of the carers

**Conclusion**

This study provided evidence about the psychological well-being of caregivers of patients with mental health problems. It is important to understand mental health of caregivers in order

**Table 2: Scores of the cares of the patients**

Care giver of the patient	Mean±Std. deviation	Range (Minimum–Maximum)
Burden Assessment Scale	72.9±20.8	48–117

**Table 3: Burden assessment of the caregivers (n=78)**

	Frequency	Percentage
Burden assessment schedule		
Minimal	23	29.0
Moderate	29	36.0
Severe	21	26.0
Very Severe	5	9.0

to develop appropriate intervention to deal with their mental health problems. Therefore, this study highlighted the need that psychological interventions should be offered not only to the patients but also to caregivers.

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### Conflicts of interest

There are no conflicts of interest.

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