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Research Article

THE UNSEEN: BURDEN IN CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA IN A TERTIARY CARE INSTITUTE

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ABSTRACT

Objectives: This study aims to evaluate the prevalence of caregiver burden in patients with schizophrenia using the burden assessment schedule (BAS).

Methods: A cross-sectional study was conducted with 100 patients diagnosed with schizophrenia and their respective caregivers from the patients admitted in the male and female wards of the psychiatric department to evaluate caregiver burden. The BAS is used to determine the burden on caregivers of schizophrenic patients.

Results: This study revealed that 51% of the caregivers had experienced moderate levels of burden. Older caregivers experienced a significantly higher burden (p=0.03), whereas residence and educational status had no significant effect on the burden. The burden was highest among parents, followed by spouses, and the burden is positively correlated with gender and older caregivers.

Conclusion: It is evident that an unaddressed burden exists among the caregivers of patients who have mental illness. It is crucial to develop strategies to lessen the load of caregiving and implement them effectively. Counseling and psychological support, though they do not directly mitigate the suffering of patients, may help improve the quality of care given by them to individuals with schizophrenia, thus overall improving the mental well-being of the whole family.

Keywords: Burden, Caregivers, Schizophrenia.

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INTRODUCTION

Mental illnesses are becoming increasingly prevalent worldwide and remain a major contributor to the global burden of disease [1,2]. The family plays a crucial role in providing support to individuals with mental illness in India [3]. A severe and chronic mental illness like schizophrenia exerts a tremendous burden on both the patient and their family members [4]. According to the global burden of illnesses, the prevalence of schizophrenia in India is estimated to be 0.3%. Previous studies (Ofovwe and Osasona [5]) suggest a 37.6% prevalence of burden among caregivers of schizophrenic patients.

Advancements in modern treatment have aided in the recovery or significant improvement of many patients; yet, some continue to exhibit deficits in various areas of functioning. The patient's relatives undergo a range of emotions, such as loss, grief, guilt, and anger. They also feel isolated and stigmatized, similar to the patient [6]. They find themselves helpless, as they are not able to share their problem with society because of the stigma attached to mental illnesses in countries like India. All these aspects of caregiving make it burdensome [7]. Caregiver burden refers to the physical, emotional, and financial demands placed on family members, friends, or other individuals outside of the health-care system by an individual's illness [8]. Caregiving involves both the patient and their long-term caregiver [9].

Families in India play a significant role in caring for individuals with various mental illnesses [10]. It is important to note that caregiver burden is a multidimensional concept, commonly categorized as an objective and subjective burden [11]. The objective burden of caregiving involves quantifiable demands such as the financial cost of illness, the time spent on care, interruptions to family routines, and the patient's dependence on the caregiver for daily living support. On the other hand, subjective burden refers to the caregiver's attitude or emotional response to the caregiving experience [12]. For family members, coping involves making continual adjustments to manage the frequent crises and disruptions in family life. The burden depends on several factors: the caregiver's age and gender, pre-morbid relationship with the patient, the patient's problems, coping strategies and perception of the patient's illness, emotional and practical support available to the family, coping behavior, and socio-cultural and ethnic variables [13]. The limited resources can further compound the problem, resulting in financial and other hardships [14]. Caregivers often experience high levels of distress and may develop minor psychiatric disorders such as anxiety and depression [15].

The tertiary care hospital in the Jabalpur division of Madhya Pradesh is also the main referral center from its nearby district for psychiatric illnesses like schizophrenia. No study on caregivers' burden has been conducted in the Jabalpur district. There is a clear shortage of research studies in India that explore the challenges faced by caregivers and the burden they experience. Hence, it is necessary to assess the burden on caregivers and provide some interventions that will reduce their stress and ultimately help in the early recovery of the patient. Hence, the objective of the current study is to assess the level of burden on caregivers of patients with schizophrenia using a burden assessment schedule (BAS).

METHODS

Research setting

A cross-sectional study was conducted in a hospital setting in the psychiatry department of NSCB Medical College, Jabalpur. The psychiatric unit has a 30-bed capacity and receives patients from nearby districts of Jabalpur. The data collection lasted from August

2023 until October 2023. A cross-sectional descriptive design is adopted. Using the purposive sampling method, 100 caregivers of patients with the diagnosis of schizophrenia of either gender admitted to the psychiatric department were recruited after obtaining informed consent from them.

A sample size of 100 was obtained using the prevalence of 37% taken from the previous study (Ofovwe and Osasona) [5]. The final sample size of 89 was estimated, rounding up to 100 considering a 95% confidence interval, Z=1.96, at a 10% margin of error.

The study subjects were individuals aged 18 years or older, diagnosed with schizophrenia based on ICD-10 criteria, receiving treatment for at least 6 months, and not having any other known chronic illness. To participate in the study, the patients needed to be mentally stable and able to give consent voluntarily. Patients with other psychiatric or medical conditions or substance-related disorders were not included in the study.

The study includes caregivers who are first-degree relatives (parents, siblings, or offspring) and spouses of a person with schizophrenia. They must have been caring for the patient for at least 6 months and not be caring for any other patient with a known chronic illness. Additionally, they must be 18 years of age or older and willing to participate in the study.

Data collection techniques

Data were gathered using a closed-ended questionnaire containing two sections:

- Section A includes two distinct socio-demographic data collection sheets that were used to get details on age, sex, education level, and other factors from the patients and caregivers, respectively.
- Section B includes the BAS [3], which was developed at the Schizophrenia Research Foundation, Chennai, India, to assess caregiver burden. A 40-item semi-quantitative scale is used to measure nine distinct areas of caregiver burden, both subjectively and objectively. It covers various domains, including finance, health, occupation, marital and sexual relations, emotional and psychosocial support, external support, caregiver's routine, and strategies. Each item can be rated on a 3-point scale: "not at all", "to some extent," and "very much". Some of the items are reverse-coded. The scores have a range of 40 to 120, and higher scores indicate a greater burden. It has four items (Items 17, 18, 19, and 20), which are to be answered only by the caregiver, who is also a spouse. There is a discrepancy between the total scores of spouses (maximum score=120) and other caregivers (maximum score=108). To overcome this discrepancy, an adjusted burden score was calculated for each patient in the previous study [16] using the formula: score obtained/maximum score × 100. After this modification, a score of 33.33 or less indicates mild or no burden; scores from 33.33 to 66.66 indicate moderate burden; and a score above 66.66 indicates severe burden. Its validity was statistically established by comparing it with the family burden schedule, with inter-rater reliability for the scale of 0.80 (kappa, p<0.01), five-test-retest reliability of 0.91 (computed for 3 months), and an alpha coefficient of 0.92 [17].

The levels of BAS score are:

- Mild: 40–60
- Moderate: 61–80
- Severe: 81–100
- Very severe: 101–120.

Statistical analysis

The data were tabulated and analyzed using MS-EXCEL and IBM-Statistical Package for the Social Sciences version 23.0. The data were expressed in percentages and proportions. Chi-square was used to obtain an association between dependent and independent variables. Logistic regression was applied to obtain significant predictors. A p<0.05 was considered significant.

Ethical consideration

Informed consent was obtained from all study participants after obtaining institutional ethical clearance.

RESULTS

The present study was conducted in the tertiary care hospital in Jabalpur, Madhya Pradesh, to assess the level of burden on caregivers of patients with schizophrenia. It was found that out of 100 patients, 78% were male. The maximum patients were in the 20–29 year age category (42%). The mean age of the patients was 28.11±8.99 SD (Table 1).

About 33% of the caregivers were aged 50 years and above. The mean age of the caregivers was 48.86±10.55 SD. The majority of caregivers were females (80%) (Table 2), and they experienced a significant caregiving burden on the BAS scale (p=0.03) as compared to male caregivers. A significantly higher caregiving burden was revealed among 30-plusage caregivers (p=0.03 for 30–39 and.02 amongst 40–49) (Table 3). However, educational status and employment revealed no significant association. Parents experienced the maximum level of burden, followed by the spouses of the patients (Table 4). No significant difference was found in the level of burden or the duration of caregiving.

Table 1: Sociodemographic details of the patient

Age	No. of patients	Percentage
20–29	42	42
30–39	38	38
40–49	8	8
50 and above	12	12
Gender		
Male	78	78
Female	22	22
Residence		
Rural	67	67
Urban	33	33
Education		
Illiterate	31	31
Primary	25	25
Middle (up to 8th)	22	22
Sr. secondary	11	11
Graduate	11	11
Occupation		
Employed	31	31
Unemployed	69	69

Table 2: Sociodemographic details of the caregiver

Age	No. of caregivers	Percentage
20–29	14	14
30–39	25	25
40–49	28	28
50 and above	33	33
Gender		
Male	20	20
Female	80	80
Residence		
Rural	67	67
Urban	33	33
Education		
Illiterate	38	38
Primary	18	18
Middle (up to 8th)	21	21
Sr. secondary	13	13
Graduate	10	10
Occupation		
Employed	75	75
Unemployed	25	25

Table 3: Association between caregiver sociodemographic variables and burden

Variables	Mean burden assessment schedule±standard deviation	p-value
Age		
20–29	70.8±16	
30–39	71.5±12.9	p=0.031
40–49	62.6±17.7	r=0.02
50 and above	72.9±14.9	
Gender		
Male	71.4±15.7	r=0.29
Female	63.5±12.5	p=0.038
Residence		
Rural	69.5±15.1	
Urban	70.4±16.1	p=0.79
Education		
Illiterate	71.5±18.1	
Primary	68.9±14.3	
Middle (up to 8th)	69.6±12.3	p=0.97
Sr. secondary	69±17.9	
Graduate	68.2±14.6	
Occupation		
Employed	68.7±15.4	
Unemployed	73±15.2	p=0.23

Table 4: Association of burden based on caregiver's relationship with the patient and duration of care

Variables	Mean burden assessment schedule±standard deviation	p-value
Relationship		
Parents	70.5±16.2	
Spouse	70.8±15	p=0.94
Sibling	68.4±15.4	
Other (son/daughter)	69.6±12.8	
Mean duration of caregiving 4.43±2.26	69.5±15.9	p=0.7

Experience of burden was most prevalent among parents (42%) and siblings (33%) (Fig. 1). It was noted that about 59% of the patients had been provided care for more than 5 years (Fig. 2). The mean burden score of the caregivers was 69.76±15.36 SD. 51% of caregivers had experienced a moderate level of burden and distress (Fig. 3).

DISCUSSION

The present study aimed to assess the caregiver burden in patients with schizophrenia and its various socio-demographic determinants. Research repeatedly highlights the substantial burden shouldered by caregivers of patients with schizophrenia [5,18,19]. Our findings paint a concerning picture, with all caregivers in our study experiencing at least some level of burden, suggesting a high prevalence of significant caregiving challenges in our demographic area. Over half of the caregivers in this study experienced moderate levels of burden. The mean burden score of the caregivers was 69.76±15.36, consistent with the findings of Ofovwe and Osasona [5], Gupta *et al.* [18], and Di Sarno *et al.* [19].

Males comprised a significant portion of our study sample, representing 78% of the 100 patients. This may be linked to the diverse pressures men face in contemporary society, including workplace stress, anxiety, depression, and financial burdens associated with family responsibilities. Patients aged 20–29 comprised the dominant group in our study, accounting for 42% of all participants, mirroring the result from a study by Srivastava [20]. The mean age of the patients was 28.11±8.99 with a standard deviation (SD). This may be because this age group is most active in all respects, be it family life, professional life, social life, or the modern lifestyle, which increases stress, leading to devastating outcomes.

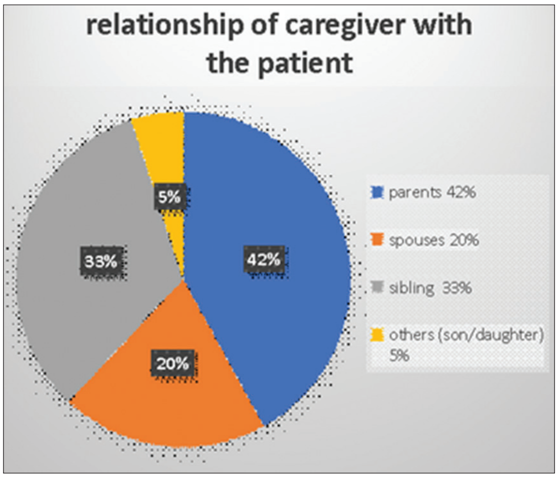

Fig. 1: Distribution of the Relationship of caregivers with the patient

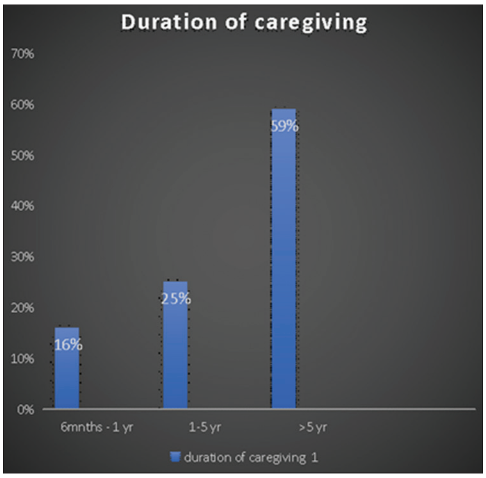

Fig. 2: Duration of caregiving among caregivers

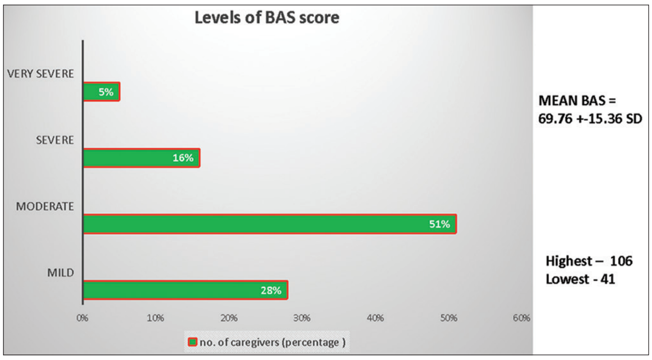

Fig. 3: Levels of BAS score

In our study, it was found that the majority of caregivers for individuals with mental illness are more than 50 years of age, reflecting the traditional role of parents as primary caregivers in Indian families. They are the major source of support for the mentally ill in India. These findings are supported by Deshmukh *et al.* [21] and Gupta *et al.* [18].

Female pre-dominance (80%) was seen in caregivers, similar to the Asian studies of Cheng and Chan [22], which reported nearly 70% of caregivers being women. In Indian families, women often take on caregiving roles due to societal expectations that they possess more caregiving skills than men. Recognizing the unique challenges female caregivers face, this point guides us in designing comprehensive support solutions for this population. The study found that caregivers who were older and female reported higher levels of burden than younger or male caregivers. Similar to the studies of Di Sarno *et al*. [19] and Kalayci *et al*. [23], but in contrast to the survey done by Gupta *et al*. [18]. Men are often less involved in hands-on caregiving, contributing to a lack of understanding and practical support for female caregivers. This can leave them feeling isolated and overwhelmed.

The majority (75%) of caregivers were employed, mirroring findings by Kalayci *et al*. [23]. Among relationships, parents comprised the largest group (42%), followed by siblings (33%) and spouses (20%). Parents reported the highest burden of caregiving, followed by spouses, despite being primarily employed. Contrary to some previous reports [5,16-18], factors such as sex, age, level of education, and employment status did not show any significant correlation with the burden of caregiving.

This study provides valuable insights into the burden experienced by caregivers of patients with schizophrenia, as well as the factors that contribute to this burden. However, there are some limitations to the study that need to be taken into account when interpreting the findings. The sample size and institutional coverage were relatively small, and the study used a cross-sectional design. Therefore, caution should be exercised when applying these findings to a broader population. Future research could replicate this study on a larger scale, using a longitudinal design to provide more robust results.

CONCLUSION

It is evident from the study that an unaddressed burden exists among the caregivers of patients suffering from mental illnesses. Almost two-thirds of caregivers of patients with schizophrenia experienced varying degrees of burden from caregiving. It is crucial to plan interventions that reduce the burden of care among the primary caregivers of individuals with schizophrenia to improve their mental well-being. Counseling and psychological support, though they do not directly mitigate the suffering of patients, may help improve the quality of care given by them to individuals with schizophrenia, thus resulting in the overall improvement of the mental well-being of the whole family.

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AUTHORS CONTRIBUTIONS

Authors Dr. Shashi Prabha Tomar and Dr. Preeti Gupta: contributed to the design of the study, guidance, supervision, and review work for the research. The final manuscript was read and approved by both authors. Dr. Sangeeta and Dr. Vaishali: contributed to collecting the articles and preparing the draft. The data analysis was done by Jagmohan Singh.

CONFLICTS OF INTEREST

I confirm that there are no conflicts of interest to disclose.

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