

DEPRESSION AND THE CAREGIVER BURDEN FOR SCHIZOPHRENIA PATIENTS

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Abstract

Background and objectives: Schizophrenia is a recurring psychiatric condition that severely impairs patients' ability to function in all major spheres of their lives. Since the deinstitutionalization policy, families, especially the primary caregiver who bears a heavy physical and emotional strain, are responsible for providing care. According to estimates, caregivers' rates of depression are higher than those of the general population. The primary caregivers' burden of care, their level of depression, and related caregiver factors were all examined in this cross-sectional study.

Methods: After gathering socio-demographic and caregiving information, 60 consenting primary caregivers of patients with an ICD-10 diagnosis of schizophrenia were evaluated for burden of care and depression using the Burden Assessment Schedule and the Patient Health Questionnaire-9.

Results: A majority of the 35 female and 25 male carers reported experiencing moderate to severe depression, and all had moderate to high levels of burden. More burden was felt by spouses ($p=0.0038$), older carers ($p=0.01$), and those with lower educational levels ($p=0.01$). Depression and caregiving burden had a statistically significant positive connection ($p=0.000$).

Conclusion: Despite the ease with which psychiatric therapies are accessible in one of India's largest metropolitan areas, caregivers continue to experience stress and depression. This may affect not only the caregiver but also the patient's care and the course of the sickness.

Keywords: Caregiver burden, Caregiving, Disability, Depression.

INTRODUCTION

A chronic condition with exacerbations and remissions, schizophrenia is a serious mental illness that affects about 20 million individuals worldwide. Each relapse is followed by a further reduction in the patient's baseline functioning. It continues to be one of the top 10 global causes of disease-related disability. Over three-fourths of patients who take antipsychotic medications report improvement in positive psychotic symptoms, but this does not mean that they will also experience improvement in other crucial daily functioning

domains like maintaining employment, social relationships, and independent living because the medications rarely affect cognitive deficits or negative symptoms [1,2]. Schizophrenia was the underlying diagnosis in 3.5 million of the 197.3 million. The average life expectancy is 20 years less than the general population, and this poses a severe challenge to the health systems, particularly in low- and middle-income nations. It is also frequently associated with psychiatric and medical comorbidities[2,3]. Schizophrenia has a disproportionately high economic burden compared to other long-term mental and physical health conditions, which is a reflection of the chronic and crippling nature of the illness, which results in both "direct" costs of health care and "indirect" costs from decreased ability to achieve real-world functional outcomes. Schizophrenia stigma causes discrimination, which restricts access to basic services including education, housing, and employment.

Patients with schizophrenia require extensive support in their daily lives as they struggle to retain social connections, keep their jobs, and live independently. The family is a significant source of support for the mentally ill in India, and most individuals with schizophrenia live with their families. Regardless of the family's strengths and coping mechanisms, caring for people with serious mental illnesses can be a heartbreaking source of stress. Although the family as a whole offers a lot of assistance, the weight of caring is frequently carried by one "primary care giver," who also has to deal with emotional and physical strain. The requirements of the caregivers may be diverse and traverse cultural boundaries [3]. Oftentimes, caregivers are less knowledgeable about the psychiatric nature of the condition, so they need education about the warning signals of a relapse, the effects of medication, and coping mechanisms for the patient's behaviour. Another substantial feature of load, in addition to financial cost, was disturbance of family interactions. Disruptions of family routine were one area in which burden was experienced. The stress of caregiving is made worse by concerns with poverty and illiteracy [3,4]. The efforts of the caretakers are sometimes overlooked. In India, carers of patients with schizophrenia have a significant role to play in overseeing daily medication administration, going with patients to doctor appointments, watching over activities of daily living (ADL), cognitive retraining, and teaching patients social and occupational skills. This is due in part to the strong familial ties present in these traditional civilizations, but it's also because there aren't enough specialists in mental health and rehabilitation to provide these treatments [4].

Even the most resourceful individual might get overburdened by the complicated and various facets of caregiving. The illness's severity and the lengthy caregiving process frequently prevent carers from achieving their own goals on a personal, social, and professional level. Due to the ongoing demands they must meet while providing care, it is not uncommon for carers to experience sadness. In fact, depression in caregivers of patients with mental illness is thought to be two times more prevalent than in the general population. Their daily routines, productivity at work, social interactions, physical health, and general quality of life can all be impacted by depression. This could have a cascade effect on the treatment given to the schizophrenic patient and how the condition develops [4,5].

The demands of the caregiver are largely unmet in a developing nation like India, where there are only 0.75 psychiatrists per 100,000 people and where the patient is the main priority, along with symptom control. Among light of this, a study was done to evaluate caregiving

stress and depression in primary caregivers of schizophrenia patients as well as related caregiving characteristics [6,7].

MATERIAL AND METHODS: This cross-sectional study included 60 caregivers of schizophrenia patients who accompanied the patients to the out-patient clinical services at Department of Community Medicine, Santhiram Medical College, Andhrapradesh, India offering a multidisciplinary comprehensive range of psychiatric care and rehabilitation services, met the criteria, and gave their consent to take part in the study. This facility serves new patients as well as 70–80 patients who come in for reviews each day. About 30–40% of these are schizophrenia patients. The study's performed from October 2021 to October 2022, data was gathered.

The following treatments were given to the study participants: A proforma for gathering sociodemographic data as well as information on relationships with patients, contact frequency, and length of treatment. Load Assessment Schedule [BAS]: The BAS, created by SCARF, was used to evaluate the caregiver burden. The level of burden was further classified as low (1–40), moderate (41–80), and high based on the total score (81–120). Patient Health Questionnaire [PHQ-9]: To evaluate depression, this structured 9-item questionnaire was administered. The PHQ-9 score might be between 0 and 27. Scores for each of the nine items range from 0 (not at all) to 3. (nearly every day) [8,9]. On this questionnaire, a score of 10 to 14 denotes moderate depression, a score of 15 to 19 denotes moderately severe depression, and a score of 20 to 27 denotes severe depression.

SPSS was used to analyse the data that was thusly collected. Percentages were determined for the sociodemographic characteristics of the study subjects and the patient care. Both the association between BAS scores and caregiver characteristics as well as the association between PHQ-9 scores and caregiver variables were investigated using the chi-square test. Using Pearson's correlation, the relationship between caregiving stress and depression was investigated. For odds ratio, the Mantel-Haenszel test was applied.

Inclusive criteria:

1. Patient and caregiver were both over the age of 18.

Exclusive criteria:

1. Primary caregivers who missed at least one month of the patient's last three months of care.
2. Carers who have previously been diagnosed with a psychiatric condition.

RESULTS

Table1: Socio-demographic profileofthecare-givers(N=60)

Variable	Caregiver(%)	95%CIof %Age
≤45years	32 (53.3)	32.6 –55.9
>45years	28 (46.6)	44.1 –67.4
Gender		
Male	25(41.6)	24 – 46.5
Female	35 (58.3)	53.5– 76
Marital Status		
Single	10(16.6)	5.6 –21.6
Married	45(75)	72.2–90.4
Divorced/Separated	2(3.3)	0.03– 7.21

Widow/Widower	3(5)	0.8–11.3
Education Status		
Primary & Middle School	32(53.3)	41.5– 65
Secondary School	10(16.6)	7.6–24.7
Graduate and above	18(30)	21.7 –43.8
Employment status		
Employed	34(56.6)	37.6 –61.1
Unemployed	26(43.3)	38.9 –62.4

60 caregivers in total, including 25 men and 35 women, took part in the study. 28 people (46.6%) were older than 45. 45 of the caregivers were married, or 75% of them. Only 18 (30%) had college degrees, while 32 (53.3%) had less than a high school diploma. Of the caregivers, 34 (56.6%) were employed.

Table2:Patient care details of the caregivers (N=60)

Variable	Caregiver (%)
Relationship to the patient	
Parent	23(38.3)
Spouse	18(30)
Children	12(20)
Sibling	5(8.3)
OtherRelatives	2(3.3)
Accommodation	
Liveswith patient	49(81.6)
Does notlive with the patient	11(14.7)
Frequency ofcontactwith thepatient	
Daily	56(93.3)
Less Frequent	4(6.6)
Yearsof provisionof care	
<5years	18(30)
≥5years	42(70)

In total, 23 (38% of the carers) were parents of schizophrenia patients, and 18 (30%) were the patients' spouses. The bulk of the carers, 49, were housemates of the patient (81.6%), and 56 (93.3%) had daily contact with the patient. 42 (70%) of the carers have been doing so for five years or longer.

Table3:Association between BAS Score and caregiver variables

Variable	Subjects with Severe burden (n=25) (%)	Subjects with Moderate burden (n=35) (%)	Odds ratio (95% C.I)	p-value
Age				
>45 years (32)	20 (80)	12 (34.2)	3.4 (1.29 – 8.9)	0.01*
≤45 years (28)	8 (32)	20 (57.1)	1.00	
Gender				

Female (35)	20 (80)	15 (42.8)	1.03 (0.40 – 2.68)	0.95
Male (25)	11 (44)	14 (40)	1.00	
Marital status				
Currently married (45)	22 (88)	23 (65.7)	2.25 (0.63 – 8.08)	0.33
Single/ separated/ widowed (15)	5 (20)	10 (28.5)	1.00	
Educational Status				
Below high school (32)	22 (88)	10 (28.5)	3.27 (1.26 – 8.49)	0.01*
High school and above (28)	16 (64)	12 (34.2)	1.00	
Employment Status				
Employed (34)	15 (60)	19 (54.2)	1.17 (0.47 – 2.90)	0.74
Unemployed (26)	11 (44)	15 (42.8)	1.00	
Duration of provision of care				
< 5 years (18)	9 (36)	9 (25.7)	1.76 (0.67 – 4.61)	0.26
≥ 5 years (42)	18 (72)	24 (68.5)	1.00	
Accommodation				
Does not Live with the patient (11)	8 (32)	3 (8.5)	3.65 (0.89 – 15.07)	0.12
Lives with the patient (49)	18 (72)	31 (88.5)	1.00	
Frequency of contact with patient				
Daily (56)	22 (88)	34 (97.1)	1.79 (0.15 – 20.63)	1.00
Less frequent (4)	2 (8)	2 (5.7)	1.00	
Relationship to the patient				
Spouse (18)	10 (40)	8 (22.8)	4.77 (1.60 – 14.24)	0.0038*
Other relations (42)	17 (68)	25 (71.4)	1.00	

*-Statistically significant

The level of burden and caregiver age were significantly correlated, with older caregivers reporting heavier loads. Additionally, there was a strong relationship between burden and education, with caregivers with lower levels of education reporting heavier loads. The strain on the spouses of schizophrenia patients was noticeably greater than that on other family members.

Table 4: Association between PHQ- 9 Score and caregiver variables

Grouping of Variable (Number)	Subjects with moderately severe and severe depression (n=24) (%)	Subjects with none, mild and moderate levels of depression (n=36) (%)	Odds ratio (95% C.I)	p-value

Age				
>45years (32)	14(58.3)	18(50)	1.82(0.71 – 4.67)	0.215
≤45years(28)	9(37.5)	18(50)	1.00	
Gender				
Female (35)	12(50)	23(63.8)	1.54(0.57 – 4.12)	0.39
Male(25)	9(37.5)	16(44.4)	1.00	
Maritalstatus				
Single/ separated/ widowed(15)9 (37.5)		6(16.6)	2.71(0.79– 9.29)	0.18
Currently married (45)23(95.8)		22(61.1)	1.00	
EducationalStatus				
Belowhighschool (32)	13(54.1)	19(52.7)	1.38(0.55 – 3.50)	0.49
Highschoolandabove (28)	10(41.6)	18(50)	1.00	
EmploymentStatus				
Employed(34)	15(62.5)	19(52.7)	1.46 (0.58–3.67)	0.43
Unemployed(26)	9(37.5)	17(47.2)	1.00	
Duration ofprovisionofcare				
≥ 5years(42)	18(75)	24(66.6)	1.40(0.52 – 3.76)	0.51
< 5years(18)	9(37.5)	9(25)	1.00	
Accommodation				
Doesn'tLive withthe patient(11)5(20.8)		6(16.6)	1.22(0.34– 4.41)	1.00
Liveswiththepatient (49) 17 (70.8)		32(88.8)	1.00	
Frequencyofcontactwith patient				
Daily(56)	22(91.6)	34(94.4)	1.43(0.12–16.49)	1.00
Less frequent(4)	1(4.1)	3(8.3)	1.00	
Relationship to the patient				
Spouse (18)	8(33.3)	10(27.7)	1.65(0.60 – 4.50)	0.33
Other relations (42)	16(66.6)	26(72.2)	1.00	

*-Statisticallysignificant

Based on their scores on the Load Assessment Schedule, all of the primary caregivers (N=60) reported moderate to high levels of burden, with 35 (53.3%) of them having moderate levels and 25 (46.7%) having high levels. 66.6% of the carers had mild to moderately severe depression, according to PHQ-9 ratings, while 6 (8%) had severe depression.

Table 5: Association between the BAS Score and the PHQ-9 score

Sample size	Variable	Mean	Standard Deviation	Correlation Coefficient (r)	p-Value
60	BAS Score	78.8	10.6	1	0.000*
60	PHQ-9 score	13.1	4.6	0.468	

*-Statistically significant

There was a significantly substantial positive connection between depression ratings and burden levels.

DISCUSSION

In this study, 35 caregivers, or 58.3% of the total, were female. In studies from different cultural backgrounds, it has been noted that the idea of family burden is a "gendered construct," with female relatives contributing the majority of caregiving. The majority of the married, middle-aged or older caregivers in this study were. The majority of the caregivers had completed elementary and middle school, and nearly half of them were unemployed. The majority of the carers were either the parents or spouses of schizophrenia patients who were also residing with the patient [10,11]. The patient was in contact with almost all of the 56 caregivers (93.3%) on a daily basis. The bulk of the carers had been doing so for five years or longer. Studies from India have shown that the vast majority of people with severe mental disorders, such as schizophrenia, live with their family members who must provide care for them for extended periods of time [11,12]. Families view providing care for their relatives with mental illness as their responsibility, and the majority of them refuse to consider the idea of separation, which would involve placing the ill member in an institution or home. According to a 1985–1986 study from the same large city, almost one-third of schizophrenia patients were living in joint or extended families, where family members made up for the patient's lack of participation. These patients also had more severe illness for a longer period of time and were severely disabled. With schizophrenia's typical course consisting of relapses and remissions, a patient's baseline functioning gets worse after each episode [12].

Patients nevertheless struggle with essential everyday functions including personal care, social connections, being gainfully employed, and living independently, even after medicine has reduced or eliminated their positive symptoms. As a result, they need a lot of support in their daily lives. Due to the high levels of stigma, there may be restrictions on access to general health care, education, housing, and work. Failure to achieve milestones in social interactions, work, and independent living can result in cyclical disability and poverty, with the majority of patients eventually needing disability benefits or being financially dependent on a family [12,13]. Given the enormity of the task at hand, caregivers can come across as being unprepared for the illness's protracted course and burdensome nature, which affects Indian families in both rural and urban areas equally. When considering the entire family as a unit, schizophrenia in one member invariably has an effect on the whole family, causing changes in the daily routine and the roles and obligations of the family members. It can become physically, mentally, and financially difficult to add the duty of caregiving to previously existent roles. The term "burden" refers to this detrimental effect on the family

[13]. Caregiving is taking on unpaid and unexpected duty for the patient with no psychological payoff because the patient finds it difficult to reciprocate because of the illness' inherent character, which makes caregiving tough. In addition to patients, caregivers struggle with stigma and are frequently shunned by society. A single caregiver is frequently responsible for taking care of a family member who has schizophrenia in urban India, where nuclear families are quickly replacing joint families and more women are seeking employment. On a personal, professional, familial, and social level, caregivers frequently find it difficult to follow their own interests and fulfil their aspirations. In this study, the BAS was burdened to varying degrees by each caregiver [13,14].

It was discovered that caregivers who are middle-aged and older had higher burden when the caregiver characteristics and burden were examined in this study. As they age, the caregivers may experience their own physical health issues, difficulties transporting the patient for routine checkups, difficulties monitoring medication, difficulties assisting the patient with personal care, financial limitations, and worries about who will take care of the patient after them [14]. While some studies indicated that the caregiver's age had no bearing on the load, others found that younger caregivers were more likely to have extra responsibilities such as working, looking after elderly parents, and raising children. Numerous research have indicated that higher load is related to the care provider's lower educational level. According to this study, caregivers with only a primary or middle school education bear a disproportionately greater burden than those with higher education. Greater access to services and resources for both the patient and themselves, as well as information for a better understanding of the patient's sickness, may be possible for those who are more educated. The financial load may be lessened by education's connection to greater work options [14,15]. In this study, the caregiver's employment status had no discernible impact on the load. When a caregiver is unemployed, they may have to spend more time with the patient and on caregiving duties. They may also be under financial difficulty since they must pay for the patient's care and treatment. Employed caregivers must balance both taking care of the patient and managing the demands of their job, especially if the patient is a small or nuclear family [15].

In this study, caregiver load for spouses of schizophrenia patients was found to be much higher than for other family members. Greater financial strain, difficulties juggling various responsibilities, trouble raising children on their own, and increased emotional stress were all observed by spouse caregivers, particularly when the patient is the principal income earner. This suggests that there is a need for targeted treatments to meet the requirements of the spouses. According to several research, the burden scores were much greater if the patient's adult son or daughter was the caregiver. This could be because they are also responsible for taking care of their own families in addition to their ailing parent. Others, however, have stated that the responsibility of being a caretaker was shared by spouses and parents [15,16]. According to one study, even though parents and spouses reported a slightly higher level of hardship, siblings reported the highest level. Women were shown to carry more burden in this study, however it was not statistically significant. Despite the fact that some studies did not find any gender differences that were statistically significant, studies on spouses showed that women carried a heavier burden because, in addition to their domestic duties, women also had to take on additional financial, caring, and social responsibilities as a result of their

husbands' illnesses. Studies where moms made up the majority of the caregivers revealed that they were more burdened, while studies where there were more male caregivers revealed that caring for others seemed to place an even greater weight on men as this is not a position that is often attributed to them [15,16,17]. Even though it was not statistically significant, this study indicated that married carers had a greater burden of care. A study from Turkey found that the burden scores of single caregivers were significantly higher than those of married caregivers, and a study from Nigeria found that the burden scores of single or widowed caregivers had increased due to greater impairment in family routines as well as financial difficulties. Daily interaction with the patient resulted in a slight but non-significant increase in load in this study.

According to Winefield & Harvey (1994), high contact was consistently linked to more responsibility, with the total number of areas of the caregiver's life impacted by caregiving responsibilities being significantly correlated with the level of contact, as was the total amount of patient-related caregiver stress, and nearly half of the caregivers would prefer the patient to live in a supervised environment. Cross-cultural research has revealed more accepting attitudes toward mental illness in developing nations [16,17]. A study from India found no appreciable difference in caregiver strain according to the length of caregiving. According to this study, although though the difference was not statistically significant, individuals who had been taking care of the patient for fewer than five years felt higher hardship. The caregiver must deal with the diagnosis during the early stages of caregiving, as well as behavioural issues brought on by psychotic symptoms, stigma, hospitalizations due to relapses, and disruptions in family routine [16,17]. As the length of time spent providing care increases, the caregiver must also deal with the patients' failure to achieve milestones in social relationships, employment, and independent living due to negative and cognitive symptoms. In this study, all carers, with the exception of a tiny number, reported mild to severe depression, with 41.3% reporting moderate to severe depression. Previous research from India found that 65% of primary caregivers scored moderately to severely depressed on the MADRS, and 24% of caregivers scored similarly on the PHQ-9, while a study from Ethiopia found that depression affected 19% of caregivers [17,18]. Although not statistically significant, depression was shown to be more prevalent in female caregivers, spouses of patients, older caregivers, those with lower educational levels, employed caregivers, and those in daily contact with patients. Depression and burden levels were found to be highly significantly associated.

CONCLUSION:

Studies have indicated that specific patient characteristics, such as the severity of symptoms, the amount of time spent in hospitals, the length of the disease, and the number of hospitalizations, may increase the burden on the family and depressive symptoms. Higher education levels were found to be negatively associated with depression in middle-income nations, according to studies on caregiver characteristics. Depression among caregivers of patients with mental illness is said to be more common than in the general population by a factor of more than two, and this needs to be addressed appropriately because it not only affects the caregiver but can also increase care costs for both the patient and caregiver and have an impact on caregiving tasks, which in turn can affect the patient's treatment and outcome for schizophrenia.

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