

## CAREGIVER BURDEN AMONG PEOPLE CARING FOR PATIENTS WITH SCHIZOPHRENIA

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### ABSTRACT

#### BACKGROUND

Caregivers of patients suffering from mental illness report burden in different areas including effects on family functioning, psychological problems, financial problems and health.

The aim of the study is to determine the sociodemographic profile and caregiver burden among caregivers of persons with schizophrenia and to study the effect of patients' psychopathology on caregiver burden scale.

#### MATERIALS AND METHODS

The present study was conducted in the Psychiatry Department, Government Medical College, Amritsar. A sample size of 34 was taken who were primary caregivers (preferably parents or spouse) of schizophrenia patients diagnosed using ICD10. Measures included caregiver's demographic variables and caregiver's burden using the Zarit burden interview and PANSS scale in patients.

Statistical Analysis- Data was analysed using SPSS software version 21.

#### RESULTS

The mean age of the caregiver was 42 SD (12.16) years. The majority of the caregivers were parents, married and employed. The mean average score of the responses to Zarit burden interview was ( $SD=59.52 \pm 20.92$ ). Majority of the caregivers experienced severe burden (52.9%), 9 (26.4%) caregivers had reported moderate burden and 6 (17.6%) had reported mild burden. The mean duration of illness was 6.89 ( $SD=5.03$ ) years. The level of burden experienced was significantly associated with total PANSS score, negative symptoms, positive symptoms, general psychopathology score and duration of schizophrenia illness ( $p=0.00$ ).

#### CONCLUSION

There is need for psychological assistance and social support for the vulnerable caregivers to help them reduce the burden levels and employ positive coping strategies.

#### KEYWORDS

Schizophrenia, Caregiver, Burden, Psychiatric.

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#### BACKGROUND

Schizophrenia is a chronic psychiatric disorder that is disabling and results in loss of social functioning among affected individuals. The burden on the caregiver emerged as a result of the shift of burden of care from hospital to families after the closure of mental hospitals.<sup>1</sup> With the advent of community psychiatry, the pressure of care of people with mental illness fall on their family. Because of this, it is important to bear in mind the attitudes of the community and the caregivers.<sup>2</sup> In India and other non-western countries, family has a major role in caregiving for

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persons with mental illness.<sup>3</sup> Caregiver is a person who meets the physical and psychological needs of the person dependant on them.

A study was conducted on Burden of care on caregivers of schizophrenia patients- A correlation to personality and coping and it was found that most of the caregivers were females. The caregivers were found to have moderate-to-high levels of burden.<sup>4</sup>

Another study was conducted on Burden on caregivers of people with schizophrenia- comparison between Germany and Britain and it was found that family burden was associated with patients' symptoms, male gender, unemployment and marital status, as well as caregivers' coping abilities, patient contact and being a patient's parent.<sup>5</sup>

The severity of the caregiver burden in schizophrenia is related to the psychopathology and medication adherence as shown in earlier studies on Effects of Psychopathology, Functioning and Anti-Psychotic Medication Adherence on Caregivers' Burden in Schizophrenia.<sup>6</sup>



In a study in Arab, the caregiver burden was found to be associated with psychopathology in the patient, caregiver lower level of education, patient's female gender and younger age, as well as patient's lower subjective QOL and needs for hospital care.<sup>7</sup>

## OBJECTIVES

1. To study the sociodemographic profile of caregivers of persons with schizophrenia.
2. To study the caregiver burden among caregivers of persons with schizophrenia.
3. To study the effect of psychopathology on caregiver burden scale.

## MATERIALS AND METHODS

The present study was conducted in the Psychiatry Department, Government Medical College, Amritsar.

A sample size of 34 was taken who are primary caregivers (preferably parents or spouse) of schizophrenia patients. Precise aim of the interview, nature of the study was explained to the patients/caregivers and written informed consent was taken. All those selected were administered the proforma containing identification, sociodemographic details of caregivers of patients of schizophrenia diagnosed as per the guidelines given in ICD-10. The caregivers of schizophrenia patients were interviewed using Zarit Burden Interview to study the caregiver burden among them.<sup>8</sup> Positive And Negative Syndrome Scale (PANSS)<sup>9</sup> was administered to the patients to study the effect of psychopathology on caregiver burden. Inclusion criteria for the caregivers included age 20 to 60 years preferably parents or spouse and residing with the patient for more than 1 year and the caregivers of patients of schizophrenia with duration of illness 1 year or more than 1 year. Patients/caregivers not giving consent and caregivers of patients of schizophrenia with mental retardation and those caregivers having past history of psychiatric illness were excluded from the study.

## Instruments

ICD-10 criteria for diagnosis of schizophrenia.

## ASSESSMENT INSTRUMENTS

1. Proforma for identification, sociodemographic details of caregivers of schizophrenia patients to elicit data such as age, gender, education, occupation, relationship of the caregiver to the patient.
2. Zarit Burden Interview (ZBI)- This is a 22-item instrument that measures the factors most frequently mentioned by caregivers as problem areas in providing care for mentally ill patients. The responses are rated on a liker scale of 0 (never) to 4 (almost always) with a total score of 0-88. The more the score, the higher is the level of burden or distress. This instrument has been widely used in various earlier studies.<sup>10,11</sup>
3. Positive And Negative Syndrome Scale (PANSS)- This was used to assess certain clinical characteristics in the patients with schizophrenia. It includes a structured

interview to assess patients on 30 items covering positive and negative symptoms as well as general psychopathology. Of the thirty items included in the PANSS, seven constitute a positive scale, seven a negative scale and the remaining sixteen a general psychopathology scale. For each item, ratings are made on a 1-7 scale of increasing levels of psychopathology ranging from absent to extreme.

## Statistical Analysis

The data was analysed using SPSS Software Version 21.0. A descriptive analysis using means with standard deviation, frequency counts and percentages was carried out. Pearson correlation coefficients (*r*) were used to address the relationship between caregiver burden and study variables. The level of statistical significance was set at *P*<0.05.

## RESULTS

The study included a total of 34 patients and their caregivers. The sociodemographic characteristics of the caregivers are shown in Table 1. Out of the 34 caregivers, 16 (47.05%) were parents, 7 (20.58%) were siblings, 1 (2.94%) a child and 10 (29.41%) were spouses. The caregivers had a mean age of 42.97 (SD=12.16) years and 55.88% were males. Majority of the caregivers were married 32 (94.11%), 2 (5.88%) were unmarried. Majority of the caregivers were employed 19 (55.88%), 12 (35.29%) were homemakers and 3 (8.8%) were unemployed. Moreover, 12 (35.29%) of the caregivers were illiterate, 4 (11.76%) held primary school degree, 3 (8.8%) had studied upto middle, 6 (17.64%) had studied upto matric, 4 (11.76%) upto secondary and 5 (14.70%) were graduates. The mean scores of the patients on the positive symptoms scale, negative symptoms scale scores and general psychopathology scales of PANSS were 20.05 (SD=4.12), 26.47 (SD=9.66), 38.76 (SD=11.20), respectively. The mean duration of illness was 6.89 (SD=5.03) years (Table 2).

Variables	Mean ± SD	
Age (years)	42.00 ± 12.16	
Variables	No.	% Age
<b>Sex</b>		
Male	19	55.88
Female	15	44.12
<b>Occupation</b>		
Employed	19	55.88
Not employed	3	8.82
Homemaker	12	35.29
<b>Relation</b>		
Children	1	2.94
Parents	16	47.06
Sibling	7	20.59
Spouse	10	29.41
<b>Education</b>		
Illiterate	12	35.29
Primary	4	11.76
Middle	3	8.82
Matric	6	17.65

Secondary	4	11.76
Graduate	5	14.71
<b>Marital Status</b>		
Married	32	94.12
Unmarried	2	5.88
<b>Residence</b>		
Urban	17	50.00
Rural	17	50.00
<b>Socioeconomic status</b>		
Lower	17	50.00
Middle	17	50.00

**Table 1. Sociodemographic Characteristics of Caregivers**

Variables	Mean ± SD
PANSS total score	85.29 ± 20.87
PANSS negative subscale score	26.47 ± 9.66
PANSS positive subscale score	20.05 ± 4.12
PANSS general subscale score	38.76 ± 11.20
Duration of illness (years)	6.89 ± 5.03

**Table 2. Clinical Characteristics of the Patients**

In our study, no statistical significance was found between caregiver demographic variables and caregiver burden (Table 3). The mean average score of the responses to Zarit burden interview was  $59.52 \pm 20.92$ . Majority of the caregivers experienced severe burden (52.9%), 9 (26.4%) caregivers had reported moderate burden and 6 (17.6%) had reported mild burden. One of the patient in the study had no burden. Significant factors that were found to be associated with caregiver burden were duration of illness, PANSS total score, negative symptoms, positive symptoms and PANSS general psychopathology score ( $p=0.00$ ) (Table 4).

Variables	Caregiver Burden				p-value
	Mild-to-Moderate	Moderate-to-Severe	Severe	Little or No Burden	
<b>Age (years)</b>					0.284 (NS)
	20-30	2	1	6	
	31-40	3	1	5	
	41-50	1	3	1	
	51-60	1	2	4	
>60	4	1	1	1	
<b>Sex</b>					
Male	4	6	9	0	0.453 (NS)
Female	4	2	8	1	
<b>Occupation</b>					
Employed	4	5	10	0	0.853
Not employed	1	1	1	0	
Homemaker	3	2	6	1	
<b>Relation</b>					
Children	0	0	1	0	0.523
Parents	5	4	6	1	
Sibling	1	0	6	0	
Spouse	2	4	4	0	
<b>Education</b>					
Illiterate	3	1	7	1	0.617
Primary	0	3	1	0	
Middle	0	1	2	0	
Matric	2	2	2	0	
Secondary	1	1	2	0	
Graduate	2	0	3	0	
<b>Marital status</b>					
Married	7	8	16	1	0.754
Unmarried	1	0	1	0	
<b>Residence</b>					
Urban	3	4	9	1	0.669
Rural	5	4	8	0	
<b>Socioeconomic Status</b>					
Lower	3	2	12	0	0.094
Middle	5	6	5	1	

**Table 3. The Relationship between Caregiver Demographic Variables and Caregiver Burden**

<b>Variables</b>	<b>Caregiver Burden</b>			<b>p-value</b>
	<b>Mild-to-Moderate</b>	<b>Moderate-to-Severe</b>	<b>Severe</b>	
PANSS total score	59.83 ± 7.58	77.33 ± 8.96	99.38 ± 16.41	R=0.841 P=0.00
PANSS negative subscale score	14.16 ± 3.62	22.33 ± 4.39	33.61 ± 5.95	R=0.888 P=0.00
PANSS positive subscale score	16.51 ± 2.62	20.55 ± 4.83	21.33 ± 3.17	R=0.459 P=0.00
PANSS general subscale score	29.16 ± 2.67	34.44 ± 8.01	44.44 ± 11.34	R=0.632 P=0.00
Duration of illness (years)	8.83 ± 5.52	4.38 ± 3.68	7.61 ± 5.08	R=0.43 P=0.00

**Table 4. Association of Caregiver Burden with Clinical Characteristics of Patients**

## DISCUSSION

The results of the study shows that caregivers of schizophrenia patients experienced moderate-to-severe level of burden. The mean Zarit burden score was 59.52 (SD=20.92). This is consistent with the earlier studies reported in literature.<sup>4,5,7</sup> The majority of the studies on caregiver burden in patients of schizophrenia report significant burden on caregivers.<sup>12,13</sup> This can be because of the personal, social and occupational deterioration in patients life in schizophrenia, which can worsen the burden on the caregivers.

In our study, significant association was found between duration of illness of schizophrenia and caregiver burden score. This is supportive of earlier similar studies.<sup>11,14</sup> As caregivers come to know about the chronic nature of schizophrenia, they may become tensed that they have to care for the patient throughout their life. Mostly, the caregivers who are parents are worried that who will care for their children after their death. In this study, significant association was found between patient's psychopathology and caregiver burden score. This is consistent with earlier studies.<sup>1,5,7,14,15</sup> In our study, significant association was found between total PANSS score, positive symptoms, negative symptoms and general psychopathology subscale score and caregiver burden score. Positive symptoms like suspiciousness/persecution, which in some cases may cause the patient to even suspect the caregiver and hostility can worsen the burden on the caregiver. This is supportive of an earlier study.<sup>16</sup> Negative symptoms causes the patients to be dependent on the caregivers economically and even for basic functions like bathing, personal care and feeding as the negative symptoms increase. This can worsen the burden on the caregiver. This finding is consistent with an earlier study.<sup>17</sup> The association between the symptom profile of the patients and caregiver burden emphasise the need of effective treatment for patients of schizophrenia to reduce the caregiver burden.

## Suggestions

To decrease caregiver burden, caregivers have to be included in the care plan and adequate information and support should be provided to the family and the caregivers. There is a need for improvement in access of patients to psychiatric services and medications, psychosocial

interventions and rehabilitation services, which can decrease the burden on caregivers.

## Limitations

The findings here are based on cross-sectional data, an important area of research will be to replicate these studies using longitudinal data. Longitudinal data might give further insight into the extent of caregiver burden. Other factors which can cause variation in burden scores can be personality of the caregivers supporting system in the family from other family members. Also, the impact of the patient's sociodemographic variables on burden was not assessed.

## CONCLUSION

There is need for psychological assistance and social support for the vulnerable caregivers to help them reduce the burden levels and employ positive coping strategies.

## REFERENCES

- [1] Awad AG, Voruganti LN. The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics* 2008;26(2):149-162.
- [2] Bhugra D. Attitudes towards mental illness. A review of the literature. *Acta Psychiatr Scand* 1989;80(1):1-12.
- [3] Thara R, Henrietta M, Joseph A, et al. Ten-year course of schizophrenia— the Madras longitudinal study. *Acta Psychiatr Scand* 1994;90(5):329-336.
- [4] Geriani D, Savithry KS, Shivakumar S, et al. Burden of care on caregivers of schizophrenia patients: a correlation to personality and coping. *J Clin Diagn* 2015;9(3):VC01-VC04.
- [5] Roick C, Heider D, Bebbington PE, et al. Burden on caregivers of people with schizophrenia: comparison between Germany and Britain. *Br J Psychiatry* 2007;190:333-338.
- [6] Lasebikan VO, Ayinde OO. Effects of psychopathology, functioning and anti-psychotic medication adherence on caregivers' burden in Schizophrenia. *Indian J Psychol Med* 2013;35(2):135-140.
- [7] Zahid MA, Ohaeri JU. Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. *BMC Psychiatry* 2010;10:71.

- [8] Zarith SH, Reever KE, Bach-Peterson J. Relatives of impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20(6):649-655.
- [9] Kay SR, Fiszbein A, Opler LA. The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophr Bull* 1987;13(2):261-276.
- [10] Hanzawa S, Tanaka G, Inadomi H, et al. Burden and coping strategies in mothers of patients with schizophrenia in Japan. *Psychiatry Clin Neurosci* 2008;62(3):256-263.
- [11] Shamsaei F, Cheraghi F, Bashirian S. Burden on family caregivers caring for patients with schizophrenia. *Iran J Psychiatry* 2015;10(4):239-245.
- [12] Magliano L, Fiorillo A, De Rosa C, et al. Family burden in long-term disease: a comparative study in schizophrenia physical disease. *Soc Sci Med* 2005;61(2):313-322.
- [13] Winefield HR, Harvey EJ. Needs of family caregivers in chronic schizophrenia. *Schizophrenia Bulletin* 1994;20(3):557-566.
- [14] Jagannathan A, Thirthalli J, Hamza A, et al. Predictors of family caregiver burden in schizophrenia: study from an in-patient tertiary care hospital in India. *Asian J Psychiatr* 2014;8:94-98.
- [15] Schene AH, Van Wijngaarden B, Koeter MWJ. Family caregiving in schizophrenia: domains and distress. *Schizophrenia Bull* 1998;24:609-618.
- [16] Gibbons JS, Horn SH, Powell JM, et al. Schizophrenic patients and their families: a survey in a psychiatric service based on a DGH unit. *Br J Psychiatry* 1984;144:70-77.
- [17] Provencher HL, Mueser KT. Positive and negative symptom behaviours and caregiver burden in the relatives of persons with schizophrenia. *Schizophr Res* 1997;26(1):71-80.