

# Role of Coping and Psychological Well-Being in Mediating Burden of Care among Caregivers of Patients with Schizophrenia

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## ABSTRACT

**Background:** Providing care to a patient with schizophrenia is a chronic stressor and the family caregivers experience a significant burden. The burden of care can be affected by the coping strategies adopted by the caregivers and their psychological well-being. **Aim:** To assess the role of coping strategies adopted by caregivers and their psychological well-being in mediating their burden of care. **Method:** The sample comprised 52 caregivers and 52 patients with schizophrenia. The caregivers were assessed with the Burden Assessment Schedule (BAS), Brief Approach/ Avoidance Coping Questionnaire (BACQ), and General Health Questionnaire-12 (GHQ-12) for their burden of care, coping strategies, and psychological well-being respectively. The patients with schizophrenia were assessed with the Positive and Negative Syndrome Scale (PANSS). Bivariate and multivariate statistical analyses were done to determine the mediators of the burden of care. **Results:** Coping strategies (action-avoidance coping score and cognitive avoidance coping score) along with psychological well-being (GHQ-12 score) determined a significant variance in the burden of care, after controlling the overlapping effect of other significant variables related to caregivers and their patients. Overall, in order of importance, the caregivers' action-related avoidance coping ( $\beta=0.274$ ,  $p<0.01$ ), their extended type of familial system ( $\beta=-0.26$ ,  $p<0.01$ ), their cognitive avoidance coping ( $\beta=0.25$ ,  $p<0.05$ ), their employed status ( $\beta=0.227$ ,  $p<0.05$ ) and their patients' scores on PANSS Positive subscale ( $\beta=0.225$ ,  $p<0.05$ ) appeared as significant predictors of the burden of care. **Conclusion:** Out of multiple factors related to the burden of care on caregivers of schizophrenia patients, an adoption of proper coping strategies by caregivers is of greater importance. Factors related to the patients and their caregivers having an overall impact on the caregiving burden should be conveyed to the stakeholders in the Indian context.

**Keywords:** caregiving, burden, coping, schizophrenia, wellbeing

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## Introduction

Schizophrenia is a psychotic disorder estimated to affect 1 out of 100 people globally [1]. These patients require long-term support and care which brings about a burden on their caregivers [2,3]. Following the deinstitutionalization movement across the world, the role of families have assumed a major portion of caregiving responsibilities and as a result the concept of 'caregiver burden' has come into existence.

Now, family caregivers are considered the core support providers for persons with schizophrenia [4,5].

The continuous course of schizophrenia and the associated long-term disability of the patients together pose chronic stress to the caregivers of such patients. Family caregivers of people with schizophrenia suffer from stress, experience high levels of burden, have a lower quality of life and greater health risks as compared to the general population [6-8]. The

caregiving of a relative with a chronic mental condition like schizophrenia is an enduring stressful task and for this, the caregivers adopt various coping strategies. Coping affects adjustment and the use of effective coping strategies has been consistently linked with higher levels of psychological well-being [9,10]. Different coping strategies employed by the caregiver are important, as they decide the effect of the stressor on the caregiver's health and adjustment which in turn, may influence the caregiver's association with the ill family member [11]. The caregivers can face the challenge of caregiving by utilizing a practical resolution such as asking for support from friends or other near ones, or they can evade their responsibilities by maladaptive coping strategies like psychoactive substance abuse [12,13]. Caregivers feel higher levels of burden in the presence of limited positive coping resources, [14,15] while adoption of less emotion-focused coping strategies results in a reduction in the perceived burden [12]. Various research works from India and abroad suggest that factors such as the age of the caregiver [4,16] unemployment, low monthly incomes [4], duration of illness [17], duration of caregiving [16] and severity of psychopathology in the patients [4,16,17] are directly related to the burden of care in the caregivers of patients with schizophrenia. Factors such as perceived social support [17], better coping strategies [16] and psychological well-being [16] of the caregivers are negatively related to the caregiver burden.

Out of multiple factors affecting the caregiving burden, the sociodemographic characteristics of the individuals can vary because of cultural and geographical differences and so are the illness-related characteristics like the severity of schizophrenia, and the nature of care by the individuals involved. If the act of caregiving a patient with schizophrenia is a stressful job, its handling is an individual business mainly dependent on the caregiver's coping abilities and psychological well-being. It will be interesting to know if we control for the possible overlapping effects of caregivers' sociodemographic characteristics as well as patients' sociodemographic and clinical characteristics, are the set of two psychological constructs of caregivers i.e., their coping and psychological well-being, still able to mediate the variance in the burden of care significantly? This approach will help us to understand the interface of three important caregiving variables in the context of schizophrenia – namely caregivers' burden of care, coping strategies adopted and their psychological well-being. This study aims to seek this pertinent issue in the Indian context and the result is supposed to be utilized in developing effective strategies to help in caregiving tasks.

## Materials and Method

This was a cross-sectional observational study in which 52 patients with schizophrenia and their 52 caregivers attending

the psychiatry outpatient department were enrolled with the help of a consecutive sampling technique. The study got clearance from the institutional ethics committee (memo no. IEC/25/17/SEP, dated November 06, 2017) and it was carried out during the period from November 2017 to October 2018.

### **Inclusion criteria for patients with schizophrenia:**

- Age range: 18-65 years.
- Diagnosed as schizophrenia according to ICD-10 DCR [18].
- More than 1-year duration of illness.
- Clinical stable.
- Availability of caregiver for the assessment.
- Written and informed consent from the patient or caregiver, as appropriate.

### **Exclusion criteria for patients with schizophrenia:**

- Comorbidity of other psychiatric condition(s) including substance use disorder.
- Comorbidity of any significant chronic physical illness
- Living in the same household with another family member with a psychiatric illness.

### **Inclusion criteria for care givers of schizophrenia patients:**

- Age range: 18-65 years.
- Written and informed consent.
- Any family member (e.g., parent, spouse, son, daughter, sibling, or another relative) who takes care of his/her patient's daily needs and medical monitoring & treatment on priority and who does not consider his/her act as a professional job.
- Duration of care: at least 1 year.

### **Exclusion criteria for caregivers of schizophrenia patients:**

- Known case of Intellectual disability or other psychiatric or physical illness which could affect his/her decision-making to participate in the study.

## **Tools for assessment**

**Socio-demographic questionnaire:** On a self-designed data sheet, socio-demographic details, of both the patients and their caregivers, were recorded.

### **The Positive and negative syndrome scale (PANSS)**

The PANSS is a 30-item scale to measure the positive, negative and general psychopathology domains of schizophrenia symptoms based on a semi-structured clinical interview. Each item is rated on a seven points rating scale. This tool is a reliable and valid tool to assess psychotic symptoms. There is higher internal reliability and homogeneity among items and Chronbach's alpha coefficient of the tool ranges from 0.73 to 0.83 [19].

The caregivers of the patients with schizophrenia were assessed with the following tools:

### ***The Burden Assessment Schedule (BAS)***

The BAS consists of 40 items rated on a 3-point scale: 1: 'not at all', 2: 'to some extent' and 3: 'very much'. Some of the items are reverse-coded. The total score ranges from 40 to 120, with a higher score indicating a higher burden. This tool has been validated against the family burden schedule of Pai & Kapur [20, 21]. This tool has an inter-rater reliability of 0.80, test-retest reliability of 0.91, and Cronbach's alpha of 0.92.

### **The Brief Approach/ Avoidance Coping Questionnaire (BACQ)**

This tool consists of a total of 12 items of which the first 6 items measure approach-oriented coping and the remaining 6 items measure avoidance-oriented coping. Each of these two categories of coping has been further organized into three different dimensions making a total of 6 different types of coping strategies to be assessed in an individual. This is a reliable and valid tool (Cronbach's  $\alpha$ : 0.68) to measure approach vs avoidant coping strategies [22].

### ***The General Health Questionnaire-12 (GHQ-12)***

This tool consists of 12 items and each one is assessed using a 4-point Likert scale (from 0 to 3). A higher score means worse psychological health. The tool is a screening of the psychological well-being of an individual over the last few weeks. It has a sensitivity of 89% and a specificity of 80%. It has reasonable test-retest reliability as well as both content validity and construct validity [23].

### ***Procedure***

The sample consisted of schizophrenia patients and their caregivers who were selected as per the laid inclusion and exclusion criteria. Out of many caregivers accompanying a patient, only one caregiver having the primary responsibility of the patient was selected. The diagnosis of schizophrenia was confirmed by a consultant psychiatrist posted in the outpatient department. After taking written and informed consent from the patients and/or their caregivers (on behalf of the patient if the patient was not in a condition to give the consent), their socio-demographic and clinical details were recorded on the self-prepared data sheet. The PANSS was applied to schizophrenia patients to make their symptom profiles while tools like BAS, BACQ and GHQ-12 were applied to the caregivers to assess their burden of care, coping strategies and psychological well-being respectively.

### ***Data Analysis***

The data were analyzed using the Statistical Package for Social Sciences 23 (SPSS 23). Preliminary analyses were done

to check the fulfilment of assumptions of normality of data. Means ( $\pm$  standard deviation) and frequency (n%) were derived to describe continuous and categorical variables respectively. Mann-Whitney U Test, Kruskal-Wallis Test and Spearman's rho correlation coefficients were utilized to examine the relationship of the burden of care with the sociodemographic & clinical characteristics of schizophrenia patients and their caregivers. The statistically significant variables, thus derived, were considered independent variables in the multiple regression analysis where the BAS total score was taken as the outcome (dependent) variable. A p value of  $<0.05$  was considered to be statistically significant.

## **Results**

### ***Sample Characteristics***

Caregivers' socio-demographic details and measurement tool scores are shown in Table 1. The socio-demographic and clinical details of the schizophrenia patients are given in Table 2.

### ***Bivariate Analyses (Correlates of the burden of care)***

The mean BAS total score of caregivers was significantly related to their occupation (employed > unemployed), background (rural > urban), socio-economic status (lower > middle), family type (nuclear > extended), and relationship with the patient (spouse > parent = other) (Table 3). Such statistically significant relationships implied that the burden of care was characteristically higher in the caregivers who were employed and spouses of the patients, as well as who belonged to a rural background, lower socio-economic status and nuclear family type. Further, a significant positive correlation was found between the mean BAS total score and the means of avoidance-oriented coping strategies score, action-related avoidance score, cognitive avoidance score, and GHQ-12 total score. Such significant positive correlations implied that the burden of care in the caregivers was higher if they used avoidance-oriented coping strategies in general and action-related avoidance & cognitive avoidance coping strategies in particular. Also, the burden of care was higher if the caregivers had poorer psychological well-being (as indicated by a higher GHQ-12 total score).

A significant negative correlation was found between the mean BAS total score of caregivers and the mean of patients' education (years). Such a significant negative correlation implied that the burden of care on the caregivers was less if the patients were educated more. Also, significant positive correlations were found between the mean BAS total score of caregivers and the mean number of past psychiatric consultations of patients as well as the means of all PANSS scores (i.e., total score and the scores on positive, negative, and general psychopathology subscales). Such significant positive correlations implied that the burden of care in the

**Table 1: Sociodemographic details and measurement tool scores of the caregivers (n=52)**

Socio-demographic variables		Mean ± SD
Age (years)		48.62 ± 13.48
Education (years)		17 ± 6.42
		<b>n (%)</b>
Sex	Male	30 (57.7)
	Female	22 (42.3)
Religion	Hindu	34 (65.4)
	Muslim	18 (34.6)
Occupation	Unemployed	14 (26.9)
	Employed	38 (73.1)
Marital Status	Single <sup>a</sup>	7 (13.5)
	Married	45 (86.5)
Background	Rural	42 (80.8)
	Urban	10 (19.2)
Socio-economic Status	Lower	42 (80.8)
	Middle	10 (19.2)
Family type	Nuclear	32 (61.5)
	Extended	20 (38.5)
Relationship with the patients	Parent	30 (57.7)
	Spouse	10 (19.2)
	Other <sup>b</sup>	12 (23.1)
		<b>Mean ± SD</b>
Duration of care giving (range 2-24 years)		6.46 ± 5.64
<b>Approach Oriented Coping Strategies Score</b>		24.88 ± 3.60
Social-Emotional Approach score		7.50 ± 2.12
Action Related Approach score		8.58 ± 1.02
Cognitive Approach score		8.81 ± 1.40
<b>Avoidance Oriented Coping Strategies Score</b>		18.15 ± 2.50
Social-Emotional Avoidance score		7.23 ± 1.54
Action Related Avoidance score		7.35 ± 1.12
Cognitive Avoidance score		3.58 ± 1.78
<b>BAS total score</b>		80.65 ± 12.65
<b>GHQ-12 score</b>		13.38 ± 2.44

<sup>a</sup>Single includes unmarried, separated, divorced, or widowed;<sup>b</sup>Other caregivers include- 4 sons, 6 siblings and 2 other relatives**Table 2: Demographic and clinical details of patients with schizophrenia (n=52)**

Socio-demographic variables		Mean ± SD	n (%)
Age (years)		31.31 ± 11.01	
Education (years)		7.27±5.30	
Sex	Male		32 (61.5)
	Female		20 (38.5)
Marital Status	Single <sup>a</sup>		30 (57.7)
	Married		22 (42.3)
Age of onset of schizophrenia (years)		24.85 ± 10.41	
Duration of schizophrenia (years)		6.46 ± 5.64	
Prior psychiatric consultations	Absent		10 (19.2)
	Present		42 (80.8)
Number of psychiatric hospitalizations in the past		0.65 ± 1.06	
PANSS Positive subscale score		16.77± 6.55	
PANSS Negative subscale score		14.50 ± 9.33	
PANSS General Psychopathology subscale score		33.62 ± 13.94	
<b>PANSS Total score</b>		64.96 ± 26.89	

SD: standard deviation; <sup>a</sup>Single includes unmarried, separated, divorced, or widowed

**Table 3: Correlates of Burden of Care with the socio-demographic variables and measurement tool scores of the caregivers (N=52)**

Variables	BAS total score Mean±SD	r <sub>s</sub> /U/H	p	
Age (in years)		r <sub>s</sub> = -0.069	0.627	
Education (in years)		r <sub>s</sub> = -0.110	0.439	
Gender	Male	80.50 ± 15.04	U = 308	0.821
	Female	80.90 ± 7.78		
Religion	Hindu	81.94 ± 14.35	U = 220	0.098
	Muslim	78.32 ± 8.41		
Occupation	Unemployed	71.86 ± 16.31	U = 148*	0.015
	Employed	83.89 ± 9.33		
Marital status	Single <sup>a</sup>	80.60 ± 9.77	U = 298	0.553
	Married	80.73 ± 16.03		
Background	Rural	83.33 ± 10.42	U = 112*	0.023
	Urban	69.40 ± 15.43		
Socioeconomic status	Lower	84.24 ± 9.80	U = 66**	0.001
	Middle	65.60 ± 12.55		
Family type	Nuclear	85.63 ± 9.76	U = 124***	0.000
	Extended	72.70 ± 12.88		
Relationship with patient	Parent	<sup>P</sup> 77.80 ± 14.04	H = 13.077**	0.001
	Spouse	<sup>Q</sup> 92.60 ± 6.38		
	Other <sup>b</sup>	<sup>R</sup> 77.83 ± 5.37		
Duration of caregiving		r <sub>s</sub> = - 0.061	0.668	
Approach-oriented coping strategies score		r <sub>s</sub> = - 0.219	0.119	
Social-Emotional Approach score		r <sub>s</sub> = - 0.238	0.090	
Action Related Approach score		r <sub>s</sub> = -0.072	0.613	
Cognitive Approach score		r <sub>s</sub> = -0.026	0.856	
Avoidance-oriented coping strategies score		r <sub>s</sub> = 0.391**	0.004	
Social-emotional avoidance score		r <sub>s</sub> = -0.192	0.173	
Action-related avoidance score		r <sub>s</sub> = 0.476***	0.000	
Cognitive avoidance score		r <sub>s</sub> = 0.686***	0.000	
GHQ-12 total score		r <sub>s</sub> = 0.474***	0.000	

SD: standard deviation; r<sub>s</sub> = Pearson's correlation coefficient; U= value of Maan-Whitney U test; H= value of Kruskal- Wallis Test; Post-hoc (Tukey) analysis: Q>P=R; <sup>a</sup>Single includes unmarried, separated, divorced, or widowed; <sup>b</sup>Other care givers include- 4 sons, 6 siblings and 2 other relatives; \*p<.05, \*\*p<.01, \*\*\*p<.001

caregivers was higher if the patients had more symptoms (whether positive or negative or severe in general) of schizophrenia as well as if the patients were taken to psychiatrists a greater number of times for consultation. Further, the mean BAS total score of caregivers was significantly related to the history of patients' prior psychiatric consultation (absent > present). This significant

relationship indicated that the burden of care was characteristically higher if the patients were never consulted with any psychiatrist (Table 4).

#### **Multivariate Analyses (Predictors of the burden of care)**

To find out the role of caregivers' psychological well-being

(i.e., the GHQ-12 total score) and their significant coping strategies adopted (i.e., the action-related avoidance coping score & cognitive avoidance coping score) in mediating the burden of care on them (i.e., the BAS scale score), a hierarchical multiple regression analysis was performed. For this regression analysis, first in Model 1, the burden of care on caregivers (i.e. dependent variable) was predicted with the help of those variables which were significantly associated with the burden of care. Such predictor variables (as shown above under bivariate analyses in Tables 3 & 4) were the occupation, background, socioeconomic status, and family type of caregivers as well as their patients' education (years), history of prior psychiatric consultation (yes vs no), counts of prior psychiatric consultations, and scores obtained on PANSS scales. Secondly in Model 2, the two target variables- (i) caregivers' psychological well-being (i.e., the GHQ-12 total score) and (ii) their significant coping strategies adopted (i.e., the action-related avoidance coping score & cognitive avoidance coping score) were also included in the list of predictor variables mentioned above.

During the regression analysis, it was ensured that there were no violations of its important assumptions like normality, linearity, singularity, multicollinearity and homoscedasticity.

To avoid the assumption of singularity, variables such as total avoidance coping score (which is a combination of action-related avoidance coping and cognitive avoidance coping scores) and PANSS-Total score were eliminated from the regression analysis. Further, the variables like caregivers' relationship with the patient, patients' PANSS- Negative score, and PANSS- General Psychopathology score failed the assumption of Multicollinearity and so were eliminated from the regression analysis. The model summary and Model significance of the multiple regression analysis are shown in Tables 5 and 6.

As shown in Table 7, in model 2, only five measures were statistically significant and they, in order of importance (i.e.,  $\beta$  values), were: Caregiver's action-related avoidance coping ( $\beta=0.274$ ,  $p<0.01$ ), Caregiver's extended family type ( $\beta=-0.260$ ,  $p<0.01$ ), Caregiver's cognitive avoidance coping ( $\beta=0.25$ ,  $p<0.05$ ), Caregiver's employed status ( $\beta=0.227$ ,  $p<0.05$ ) and Patient's PANSS Positive subscale score ( $\beta=0.225$ ,  $p<0.05$ ).

## Discussion

This study brings about a comprehensive assessment of possible socio-demographic and clinical factors related to

**Table 4: Correlates of Burden of Care with the Demographic and Clinical details of the patients with schizophrenia (N=52)**

Variables	BAS total score	$r_s/U$	p
<b>Patient's socio-demographics</b>			
Age (in years)		$r_s = 0.149$	0.292
Education (in years)		$r_s = -0.337^*$	0.015
Gender	Male	$80.50 \pm 15.04$	U = 308
	Female	$80.90 \pm 7.78$	
Marital status	Single <sup>a</sup>	$80.60 \pm 9.77$	U = 298
	Married	$80.73 \pm 16.03$	0.553
<b>Patient's clinical characteristics</b>			
Age of onset of schizophrenia (years)		$r_s = -0.048$	0.735
Duration of schizophrenia (years)		$r_s = -0.061$	0.668
Prior psychiatric consultations	Absent	$92.20 \pm 9.15$	U = 70**
	Present	$77.90 \pm 11.85$	
Number of psychiatric hospitalizations in the past		$r_s = 0.349^*$	0.011
PANSS Positive subscale score		$r_s = 0.402^{**}$	0.003
PANSS Negative subscale score		$r_s = 0.358^{**}$	0.009
PANSS General Psychopathology subscale score		$r_s = 0.496^{***}$	0.000
PANSS Total score		$r_s = 0.460^{**}$	0.001

SD: standard deviation;

$r_s$  = Spearman's rho correlation coefficient;

U= value of Maan-Whitney U test; \* $p<0.05$ , \*\* $p<0.01$ , \*\*\* $p<0.001$ ;

<sup>a</sup>Single includes unmarried, separated, divorced, or widowed

**Table 5: Hierarchical Multiple Regression Analysis: Model Summary<sup>a</sup>**

Model	R		Adjusted R Square	Std. Error of the Estimate	R Square Change	Change Statistics			
	R	Square				F Change	df1	df2	Sig. F Change
2	0.876 <sup>c</sup>	0.767	0.710	6.81614	0.116	6.768	3	41	0.001

<sup>a</sup>Dependent Variable: Burden Assessment Schedule (BAS) total score.

<sup>c</sup>Predictor Variables: Patient's Education, Prior Psychiatric Consultations, PANSS Positive subscale score, Caregiver's Occupation, Caregiver's Background, Caregiver's Socioeconomic Status, Caregiver's Family type, GHQ-12 total score, Action-related avoidance coping score, and Cognitive avoidance coping score.

**Table 6: Model Significance of Hierarchical Multiple Regression Analysis: ANOVA<sup>a</sup>**

Model		Sum of Squares	Mean Square	F	Significance
2	Regression	6258.921	625.892	13.472	0.000
	Residual	1904.848	46.460		
	Total	8163.769			

<sup>a</sup>Dependent Variable: Burden Assessment Schedule (BAS) total score

**Table 7: Model Coefficients of Hierarchical Multiple Regression Analysis**

Model		Unstandardized Coefficients		Standardized Coefficients	P value
		B	Std. Error	Beta	
2	(Constant)	51.69	13.67		0.000
	Patient's Education (years)	-0.300	0.277	-0.126	0.285
	Prior Psychiatric Consultations (Present)	-3.54	2.95	-0.111	0.237
	PANSS Positive subscale score	0.435	0.195	<b>0.225</b>	<b>0.031</b>
	Caregiver's Occupation (Employed)	6.42	2.73	<b>0.227</b>	<b>0.024</b>
	Caregiver's Background (Urban)	5.06	3.92	0.159	0.204
	Caregiver's Socioeconomic Status (Middle)	-6.09	3.896	-0.192	0.126
	Caregiver's Family type (Extended)	-6.69	2.407	<b>-0.260</b>	<b>0.008</b>
	GHQ-12 total score	0.038	0.553	0.007	0.945
	Action-related avoidance coping score	3.095	1.061	<b>0.274</b>	<b>0.006</b>
	Cognitive avoidance coping score	1.780	0.739	<b>0.250</b>	<b>0.020</b>

the burden of care on the caregivers of schizophrenia patients in the Indian context. On bivariate analyses done in this study, it was found that the burden of care on caregivers was characteristically higher if they were spouses of the patients, employed, belonged to a rural background & a nuclear familial system and had lower socioeconomic status as well as if they adopted avoidance-oriented coping strategies (especially action-related avoidance and cognitive avoidance) and had poorer psychological well-being. The burden of care on them was also characteristically higher if their patients were educated less or the patients had greater

schizophrenia symptoms and illness severity or the patients were either never consulted with any psychiatrist or they were taken to such consultations a greater number of times.

These findings are supported by outcomes of many research works done in India where factors such as the severity of psychopathology in schizophrenia patients were positively correlated with the caregiver burden while the factors like perceived social support, better coping strategies, and psychological well-being of the caregivers were negatively correlated to the caregiver burden [16,17]. The findings of

this study are in accordance with a recent study done in China where factors like the severity of psychopathology in schizophrenia patients, low monthly incomes of caregivers and their fewer family coping strategies were directly related to caregiver burden [4]. A significantly higher burden of care was observed in the employed caregivers of the present study. Logically, employment gives financial safety but it puts a further burden on a caregiver if one has to make a balance between handling a family member with symptomatic schizophrenia patient and one's demands for employment. However, this finding of our study is in contrast to one in the Chinese study where the unemployment of caregivers was directly related to the burden of care [4].

In line with our research question, the most important finding of our study was that the set of two constructs of caregivers i.e. their coping and psychological well-being was still capable to predict the variance in caregiving burden significantly despite controlling the possible overlapping effects of other significant variables related to the caregivers and their patients. Finally, in order of importance, factors such as caregivers' adoption of action-related avoidance coping strategy, their extended familial system, their adoption of cognitive avoidance coping strategy, their employed status and their patients' positive schizophrenia symptoms appeared as significant mediators of the caregiver burden. Thus, between the two constructs of caregivers targeted in the research question, coping was a significant mediator of the caregiving burden while psychological well-being (as assessed on the GHQ-12 screening instrument) did not appear significant on the multivariate (regression) analysis despite its significant association with the caregiver burden reflected on the bivariate (correlation) analysis. Overall, this finding appears reasonable in the context where the caregivers were included in the study only when they were free from any significant physical or psychiatric morbidity. The existing literature suggests that caregivers often face increased psychological stress due to the financial, psychological and social demands of chronically ill patients and depressive disorders are frequently reported psychiatric disorders by caregivers of patients with chronic mental illness [25,26]. A comprehensive assessment of various psychiatric comorbidities in the caregivers of schizophrenia patients may clarify the issue.

Conceptually, psychological coping is defined as a tool used by the psyche to overcome overwhelming stress or anxiety. According to Finset et. al. [22] psychological coping can be of two opposite types- approach-oriented coping & avoidance-oriented coping, and there are three distinct domains of each of these two types of coping, to reflect the different psychological constructs of an individual:

a) The *cognitive* domain reflects an individual's attitudes to current and long-term coping with problems; b) The *socio-*

*emotional* domain reflects an individual's social support seeking as well as emotional expression and engagement; and c) The *action-oriented* domain reflects an individual's active tackling or action related diversion, as well as motivation for activities. A finding of coping strategies like action-avoidance and cognitive avoidance used by the caregivers of this study reflect that they had attitudes and related actions to avoid the ongoing stress of caregiving. These findings are further supported by the observations of Folkman & Lazarus, [27] who have conceptualized avoidance-oriented coping in two different ways: (1) a passive way of relating to stress or (2) an active orientation away from the stressor, such as denial, diversion or escape. To handle any ongoing stress, approach-oriented coping strategies are of better help than avoidance-oriented coping strategies and thereby the latter can be inferred to be easily associated with a higher caregiver burden. A recent Indian study [28] has found that frequent use of adaptive coping mechanisms by the caregivers of schizophrenia patients was associated with a lower level of residual symptoms and better functioning of the patient, and lower psychiatric morbidity among the caregivers. In contrast, a repeated adoption of maladaptive coping mechanisms is linked with poorer outcomes in both patients and their caregivers.

A finding of the nuclear familial system creates a higher caregiving burden than the extended familial system is an important observation of this study which should be understood in the context of a changing familial system in our society. In India, the joint/extended family system with strong networks of kinship ties has been known traditionally to provide better care for persons with mental illnesses. However, over the last couple of decades, breakdowns are being seen in Indian familial structures which should be seen in the light of a steady rise in the participation of women in working places as well as an increased migration of the youth (inside or outside of India) for the sake of better financial avenues. Resultantly, people have to make considerable compromises or look for long term hospitalization to care for their patients who require additional support beyond what the family can provide [29].

A significant and persistent contribution of the PANSS Positive subscale score in predicting the caregiver burden indicates that the positive symptoms of schizophrenia patients like delusions, hallucinations, and agitated behaviours were significant contributors to the caregiver burden. However, a particular set of psychotic symptoms may not have the most significant impact on the caregiving burden. Some of the research works done earlier claim that the positive symptoms of schizophrenia are more burdensome while others claim that the negative symptoms of schizophrenia such as emotional blunting, lack of volition, and social withdrawal create a higher burden for the caregivers

[30]. Overall, there is agreement that a high level of symptomatology has a significant direct relationship with the burden of care among the caregivers schizophrenia patients [30].

### Limitations

This study had several limitations. A low power due to a relatively smaller sample size might have prevented the establishment of statistically significant effects. However, this study was able to find a meaningful association of the caregiving burden with important variables of schizophrenia patients and their caregivers. As this was a cross-sectional observational study, it was difficult to establish any cause-effect relationship and for that, a longitudinal study with a larger sample size would be required. Although we examined the role of coping and psychological well-being of caregivers as predictors of their caregiving burden, the latter could also predict the former suggesting a bidirectional association.

### Conclusion

Out of multiple factors related to the burden of care on caregivers of schizophrenia patients, an adoption of proper coping strategies by caregivers is of greater importance. Factors related to the patients and their caregivers having an overall impact on the caregiving burden should be conveyed to the stakeholders in the Indian context.

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