

# Burden of Care on Caregivers of Schizophrenia Patients: A Correlation to Personality and Coping

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## ABSTRACT

**Background:** Schizophrenia is a mental disorder where the caregivers are likely to face increasing levels of burden and stress. The present study aims to explore the relation between burden of care on the caregivers of schizophrenic patients with various psychological parameters including their coping strategies, personality type, overall quality of life and socio-demographic details.

**Materials and Methods:** The participants included in the study (n=110) were administered a socio-demographic data sheet and questionnaires to assess their personality type, burden, quality of life, and coping mechanisms of having a schizophrenic in the family. These questionnaires were administered in individual setting. Their informed consent was taken prior to the administration of tools and their privacy was taken care of. The data obtained was analysed statistically.

**Results:** Most of the caregivers were females. The caregivers were observed to have moderate and high levels of burden. Burden on the caregivers showed a significant correlation with psychoticism and their overall quality of life. A significant correlation was seen between the levels of coping and extrovert type of personality, and also with the environmental health of the caregivers. Caregivers belonging to nuclear families coped better than those of joint families.

**Conclusion:** The study concludes that certain personality traits like psychoticism and certain social traits such as living in joint families can increase the risk of caregiver burden in looking after family members suffering from schizophrenia. A need for psychological assistance for the vulnerable caregivers to help them reduce the burden levels and employ positive coping strategies has, therefore, been emphasized in our study.

**Keywords:** Mental illnesses, Psychiatry, Type of personality

## INTRODUCTION

As per WHO estimates, around 450 million people are suffering from a mental or behavioral disorder worldwide [1]. Neuropsychiatric disorders including schizophrenia, depression, bipolar disorder and alcohol-use disorders constitute of the leading causes of years lived with disability [1,2]. Schizophrenia has a global prevalence of 0.3-0.7%, with 3 million Indians suffering from the same [3]. Schizophrenia is a chronic psychiatric disorder, and its effects can be classified at three levels; first the patient who undergoes personal suffering, secondly the caregiver and/families for the burden of care along with the added responsibility of transitioning the relative from inpatient to the outpatient treatment, and the thirdly the society as a whole for suffering from frequent hospitalizations and long-term financial and psychosocial support [4].

The care givers of schizophrenia patients are likely to face increasing levels of burden and stress. Burden of care does not only include the subjective dimension comprising of impact and consequences on the mental health of the caregivers, but also the objective dimension which includes dealing with patient's symptoms and behavior, and changes in the household routine and family relations [5]. A study by Vasudeva et al., has concluded higher levels of burden in caregivers of schizophrenia patients as compared to those of bipolar disorder patients, especially in terms of external support, caregiver routine and relationship with other family members and friends [6]. A study by Rudnick [7] shows the importance of participatory research in the field of mental health particularly to explore the burden on caregivers. [7]. Gutierrez-Maldonado et al., found high levels of burden associated with factors like less education and young age of the schizophrenia patient [8]. Similarly, Juvang et al., in a study conducted in China concluded that the age of the caregivers was positively correlated to their burden whereas the education level exhibited a negative correlation [9]. Grandon et al., conducted a study in Chile and concluded that the burden on the caregivers was based on the clinical profile of the patient, personality of

the caregivers and from the various forms of social support to the family [10]. In order to ease this burden and to prevent relapses, interventions need to be customized according to the problems faced by the family members as the caregivers. A study conducted in the UK concluded that the coping style employed by the caregiver was associated with the caregiver burden and psychological distress [11]. Similar observations were drawn in another study where problem-solving coping styles were related to lower levels of burden whereas avoidance coping was strongly associated with high levels of burden and distress [12]. The present research focuses on both the burden of care on the family members of patients with schizophrenia and the coping strategies employed by them. It aims to identify and establish a relationship, if any, as to how coping strategies and caregiver's personality type influence the levels of burden. It also aims to find out the influence of higher levels of burden, if any, on the physical, psychological, social and environmental health of the caregiver. It is essential to shed more light on this topic in countries like India so that life-time loss in productivity of both the patient and the caregiver can be minimized, and so that utilization of the available limited resources can be made optimally.

## MATERIALS AND METHODS

An approval was obtained from the Institutional ethics committee of Kasturba Medical College, Mangalore before the commencement of the study. The cross-sectional study was carried out in the Department of Psychiatry, Kasturba Medical College, Mangalore, India. Caregivers of schizophrenia patients admitted in the Department of Psychiatry of our institution, non-governmental organizations and nursing homes were enrolled in the study in accordance with the inclusion criteria, after obtaining permission from the authorities concerned. They were informed about the details of the study and informed consent was obtained from each participant before undertaking the research.

The sample size for the study was calculated as 110 with 95% confidence level and 80% power using the formula:  $S=4pq/E^2$ ; where S = sample size, p = proportion of caregivers with the highest level of burden, q = (100 – p) and E = relative error.

The following inclusion criteria was followed: (1) Primary Caregiver of patient with schizophrenia diagnosed under ICD-10 or DSM IV Criteria at least 6 months prior to the date of interview, (2) Primary caregiver who is defined as the member of the family who has been the most involved in the care of the patient and has lived with the patient for at least 12 months, and (3) Caregiver between the age of 18 and 45. The following participants were excluded from the present study: (1) Those that did not fit into the inclusion criteria, (2) Caregivers suffering from psychiatric or physical disorder which might interfere with the care of patients and his/her co-operation during interview.

Basic socio-demographic details of the participants were collected which included their age, sex, marital status, residence, and occupation. Besides, questionnaires that assess the personality, stress, quality of life, and coping were administered to the participants after these were translated into the local dialect with the help of a bilingual expert. The questionnaires were distributed to the participants and assistance was provided by the interviewer. The following instruments were used to collect the data and the scoring was done in accordance with the guidelines given in the respective instruments.

1. Family Burden Interview Schedule (FBIS) to assess the burden on the caregiver [13].

The burden scale ranging from 0-48 was divided into three classes: those with scores 0-16 suffered from mild burden, those with scores of 17-32 suffered from moderate burden and those with scores of 33-48 suffered from severe burden.

2. Family Coping Questionnaire (FCQ) to assess the coping strategies used by the caregiver [14].

The coping scale ranging from 1-24 was divided into two classes. The scores ranging from 1-12 indicated fair levels of coping, whereas those ranging from 13-24 indicated good levels of coping by the caregivers.

3. WHOQOL-BREF Questionnaire to assess the quality of life of caregiver [15].

The quality of life of caregivers was assessed by grading each of the four domains listed on the WHOQOL-BREF questionnaire with scoring system of 0-100.

4. Eysenck's Personality Questionnaire – Revised (EPQ-R) to assess the caregiver's personality.

The type of personality of the caregivers was assessed by grading each of the personality types on a standard scale of 1-10.

## STATISTICAL ANALYSIS

The data was analysed statistically using SPSS version 17.0. Unpaired t-test was used to compare independent mean values. Relation between the burden of stress and coping strategies was estimated using chi square test. Relations between burden on the caregiver and his/her overall quality of life, personality and socio-demographic details, were also assessed using chi-square test. P-value less than 0.05 were considered significant.

## RESULTS

### Socio-demographic characteristics

The majority of the caregivers were females (n=80, 73%). Most of the study participants were aged between 36 and 45 y with mean age being 43.82 y. A proportionately larger number of the caregivers belonged to nuclear families (n=68, 62%). It was observed that the majority of the participants were married (n=84, 76%). A larger

proportion of the participants (55%, n=60) belonged to the rural community, others being from urban background (45%, n=50).

### Assessment of burden levels, coping pattern, personality type and quality of life of the caregivers

The majority of the caregivers (72.7%) experienced moderate burden with mean scores being  $25.35 \pm 4.43$  [Table/Fig-1]. It was observed that disruption of family leisure was the most common manifestation of the burden of having schizophrenia patients in the family (61%, n=67), while the others in decreasing order included impaction on mental health of the caregiver (56%, n=62), disruption of family routine activities (52%, n=57), disruption of family interaction (48%, n=53), financial burden (39%, n=43) and compromise on the physical health of the caregivers (36%, n=40).

The majority of the caregivers (63.6%, n=70) employed good coping strategies [Table/Fig-2]. On evaluating the methods employed by the caretaker to cope with the burden of having schizophrenia patients in the family, majority copied well with mature coping mechanisms. In decreasing order of frequency, these included finding out information and understanding the patient's condition (92%, n=101), by encouraging the patient for social involvement (91%, n=100), by positive communication with the patients (85%, n=94), and by distracting themselves by increasing social involvement and by helping others (65%, n=72). The other methods employed by the caretakers were immature mechanisms like resorting to resignation (40%, n=44), resorting to coercion (33%, n=36), and by avoiding problems (29%, n=32). Regarding the quality of life of the caregivers, the participants showed higher scores in terms of environmental health as compared to the other three domains of social relationships, psychological health and physical health in decreasing order of mean scores [Table/Fig-3]. For the type of personality of the caregivers, it was observed that the participants showed higher scores in psychoticism as compared to extroversion and neuroticism [Table/Fig-4].

### Relation of burden levels with coping, personality, quality of life and socio-demographic details

In our aim to assess if the levels of burden suffered by the caregiver was influenced by the coping mechanisms (mature or immature) employed by them; no significant correlation ( $p=0.258$ ) was observed between the coping mechanisms and the levels of burden experienced by the caregivers [Table/Fig-5]. For the aim to study if the burden levels varied with the type of personality of the caregiver, a significant correlation ( $p=0.028$ ) was observed between burden levels and psychoticism i.e. stronger the caregiver's personality towards psychoticism, more is the level of burden experienced by the caregiver. No such correlation was however, observed with extrovert personality types and neuroticism [Table/Fig-6]. Similarly, for comparisons between the levels of burden with quality of life of caregivers, it was observed that there was a significant decrease in the quality of life in all four domains with increasing levels of burden amongst the caregivers [Table/Fig-7]. The caregiver's age ( $p=0.299$ ), sex ( $p=0.053$ ), marital status ( $p=0.074$ ) and type of family ( $p=0.114$ ) did not have any significant influence on the levels of burden suffered by them.

### Relation of coping pattern with personality, quality of life and socio-demographic details

It was observed that the coping levels were significantly correlated to the extrovert type of personality ( $p=0.014$ ); i.e. extroverts employed better coping strategies, as compared to neuroticism and psychoticism, in dealing with the burden associated with having a schizophrenia patient in the family [Table/Fig-8]. Our study also observed a significant correlation between the coping levels

and the fourth domain (environmental health) of the quality of life ( $p=0.037$ ); i.e. better coping strategies employed by the caregiver led to a healthier environment [Table/Fig-9]. The caregivers living in nuclear families were observed to employ better coping strategies of having schizophrenia patients in the family as compared to their counterparts who lived in joint families [Table/Fig-10]. The correlation of levels of coping with socio-demographic details of the caregiver's age ( $p=0.079$ ), sex ( $p=0.122$ ) and marital status ( $p=0.055$ ), were not observed to be statistically significant.

Burden (Scale)	Number (n)	Percentage (%)	Mean Burden $\pm$ SD
Mild (0-16)	22	20.0	10.81 $\pm$ 4.578
Moderate (17-32)	80	72.7	25.35 $\pm$ 4.435
Severe (33-48)	8	7.3	36.25 $\pm$ 1.732

[Table/Fig-1]: Levels of burden amongst the caregivers SD – Standard Deviation

Coping Levels (Scale)	Number (n)	Percentage (%)	Mean $\pm$ SD
Poor (1-12)	40	36.4	11.40 $\pm$ 0.820
Good (13-24)	70	63.6	15.33 $\pm$ 2.035

[Table/Fig-2]: Levels of coping strategies employed by the caregivers SD – Standard Deviation

Quality of Life	Minimum	Maximum	Mean $\pm$ SD
D1 (Physical health)	19	69	50.60 $\pm$ 9.755
D2 (Psychological health)	31	75	51.20 $\pm$ 10.449
D3 (Social Relationships)	19	94	54.87 $\pm$ 20.323
D4 (Environmental health)	19	100	62.31 $\pm$ 19.325

[Table/Fig-3]: Descriptive statistics for assessment of quality of life of the caregivers SD – Standard Deviation

Type of Personality	Minimum	Maximum	Mean	SD
Psychoticism (P)	4	10	7.09	1.691
Neuroticism (N)	1	9	4.49	1.989
Extroversion (E)	1	9	4.93	2.609
Lie Score (L)	3	5	5.20	0.825

[Table/Fig-4]: Descriptive Statistics for personality type of the caregivers SD – Standard Deviation

Burden	Good coping strategies (N, %)	Poor coping strategies (N, %)	Total
Mild	12, 17.2%	10, 25%	22, 20%
Moderate	50, 71.4%	30, 75%	80, 72.7%
Severe	8, 11.4%	00, --	8, 7.3%
Total	70, 100%	40, 100%	110, 100%

[Table/Fig-5]: Burden levels and coping strategies employed by the caregivers Chi square value= 2.701,  $p=0.258$

Burden	Psychoticism	Neuroticism	Extroversion
Mild (n=22)	5.909	4.000	5.727
Moderate (n=80)	7.350	4.600	4.850
Severe (n=8)	7.707	4.750	3.500
p-value	0.028	0.659	0.328

[Table/Fig-6]: Burden levels and mean scores for the type of personality of the caregivers

Burden	D1 (Physical)	D2 (Psychological)	D3 (Social)	D4 (Environmental)
Mild (n=22)	58.545	61.363	78.454	77.272
Moderate (n=80)	49.050	49.275	51.200	60.200
Severe (n=8)	44.250	42.500	26.750	42.250
p-value	0.005	<0.001	<0.001	0.002

[Table/Fig-7]: Burden levels and mean values for the quality of life (QOL) of the caregivers

Coping levels	Psychoticism	Neuroticism	Extroversion
Good (n=70)	7.371	4.771	6.050
Poor (n=40)	6.600	4.000	4.285
p-value	0.104	0.169	0.014

[Table/Fig-8]: Coping levels and mean value of personality scores for the caregivers

Coping levels	D1 (Physical)	D2 (Psychological)	D3 (Social)	D4 (Environmental)
Good (n=70)	51.900	51.850	61.850	69.450
Poor (n=40)	49.857	50.829	50.886	58.229
p-value	0.460	0.731	0.053	0.037

[Table/Fig-9]: Coping levels and mean value of the scores for the quality of life of the caregivers

Coping levels	Nuclear families (n, %)	Joint families (n, %)
Good (n=70)	66, 97.0%	04, 09.5%
Poor (n=40)	02, 03.0%	38, 90.5%
Total (n=110)	68, 100%	42, 100%

[Table/Fig-10]: Coping levels and family type of the caregivers

## DISCUSSION

Most of the caregivers in the present study were females, and aged between 36 and 45 y, similar to a study conducted in Spain that observed a female preponderance among caregivers [10]. Burden levels of the caregiver neither showed a significant correlation with the socio-demographic details of the caregiver nor with those of the schizophrenic patients. This is in concordance with the study conducted in Egypt which also established similar results [16]. In contrast, a study conducted in China observed a positive correlation between age of the caregiver and the burden levels, and a negative correlation between the education level of the caregiver and the burden levels [9]. A study conducted by Vasudeva et al., in India shows higher levels of burden in caregivers of nuclear families as compared to those living in joint families [6]. Our study established that the levels of burden were higher in caregivers with a greater inclination towards psychoticism. The higher levels of burden were also significantly related to all the four domains of quality of life which included physical health, psychological health, social relationships and environmental health.

In the present study, 80% of the caretakers experienced burdens in the moderate and high range of having a schizophrenic in the family. The observation is in concordance with a study carried out in Egypt where high levels of burden were reported in the caregivers [16]. The manifestations of the burden were mostly in the form of disturbance of family life and impaction on the mental health of the caregiver, as compared to the study conducted in Egypt where the highest scores of burden were related to investing time and physical efforts in caring for their mentally ill family members, being sad and worried, and spending money on them [16]. A similar study conducted in Israel concluded that the highest burden was related to apprehension and the second highest was related to financial burden [7]. Another study conducted in India concluded that the pattern of burden in caregivers of schizophrenia patients and those with bipolar disorder were almost similar except in areas of external support from other family members, caregiver routine, and in terms of maintaining cordial relationships with family and friends, which was higher in caregivers of schizophrenia patients [6]. Our study observed disruption of routine family activities, disruption of family interaction, financial burden, and effect on physical health of other family members as the other manifestations of the burden experienced by the caregivers.

Various interventions need to be employed by caregivers in order to combat the burden of having a schizophrenia patient in the family. Coping strategies have been categorized into two main types; emotion-focused and problem-focused [17]. In particular, the

coping styles 'criticism/coercion', 'over-protectiveness', 'emotional over-involvement' and 'resignation' were found to be associated with higher levels of caregiver burden, and the coping style 'warmth' was found to be associated with lower levels of caregiver burden [11]. It was also concluded in another study that problem-focused strategies were more often employed by the caregivers [12]. Our study established that majority of the caregivers undertook mature coping mechanisms including gaining more information regarding the patient's condition and encouraging patient for social involvement. Similar results were established in the research conducted by Chakrabarti et al., [18] and Hassan et al., [16] where emotion-focused coping mechanisms which included self-controlling, positive reappraisal and escape-avoidance were employed by the caretaker. Another study conducted in India by Kate et al., highlights the importance of better control of patients' symptoms on reducing the burden and better employment of coping strategies [19].

Our study did not observe any correlation between the levels of burden and the coping strategies employed by the caregivers, which concludes that the levels of burden are independent of the employed coping strategies, mature or immature. However, a significant correlation was observed between the coping levels of the caregivers with the extrovert type of personality in our study indicating that extroverts had better coping strategies in dealing with a schizophrenic patient in the family as compared to the other personality types. It was also seen that caregivers employing good coping patterns had better environmental health. Also, as compared to another study conducted in India which concluded that caregivers of joint families coped better with the burden of care [20], our study established that those of nuclear families employed better coping strategies to reduce the burden. This finding in our study can be attributed to less interpersonal differences in nuclear families and the ability to distribute resources optimally amongst the lesser family members as compared to those in joint families.

## LIMITATIONS OF THE STUDY

Since the coping strategies employed by the caregivers are dynamic, our study does not predict to what extent the coping strategies will change in the future and what influence it will have on their quality of life. Most of the study participants in the present study were females. Caregiver burden may vary between males and females and need to be explored on a larger sample. Besides, factors such as educational and income status of the caregivers can have an influence on the results and thus, future studies are suggested on a larger sample with inclusion of these parameters.

## CONCLUSION

Burden experienced by the caretakers of schizophrenic patients is mostly of moderate and high levels. Caregivers with higher inclination to psychoticism are seen to experience higher levels of burden as compared to the other personality types. This in turn affects their quality of life adversely. There is a need for addressing the stress levels of the caregivers in order to help them improve their quality of life and enhance their well-being, and to also provide them with psychological counseling to reduce their burden and increase their lifetime productivity in the society. However, the various coping

strategies, mature or immature, employed by the caregivers do not seem to have an effect on the levels of burden experienced by them. It is seen that caregivers with an extrovert type of personality and those belonging to nuclear families have a better way of coping with the effects of having schizophrenia patients in the family. Better ways of coping also lead to an overall improvement in environmental health.

This present study highlights the need to counsel the caregivers as to how to deal with various situations faced due to having schizophrenia patients in the family. The mode of interaction and coping strategies determine the course of the illness in these patients, and hence positive interaction can improve the quality of life of both the caregivers and the patients, thereby increasing the lifetime productivity of these individuals.

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