

# Family Burden and Coping in Caregivers of Chronic Schizophrenia – A Hospital based Study

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**Abstract:** **Background:** The demands of being involved in the care of a seriously mentally ill relative have both an emotional and a practical impact on the caregiver. For a given amount of burden, the individual levels of distress show variable considerations because it varies according to their ways of coping. **Aim and objectives:** To assess the burden of caregivers of chronic schizophrenia. To assess coping strategies adopted by the caregivers of chronic schizophrenia. To study the relationship of burden and coping strategies in caregivers of chronic schizophrenia. To assess the relationship of burden of the caregivers with the global assessment of functioning of the patients of chronic schizophrenia. **Materials and methods:** The study was conducted in the Department of Psychiatry, Assam Medical College and Hospital, in upper Assam (Dibrugarh) with a sample size of 30 primary caregivers of equal number of patients of Chronic Schizophrenia. Diagnosis of Schizophrenia was made as per guidelines listed in ICD-10. The study was of cross sectional, exploratory research design conducted with the use of scales and questionnaire. **Results:** Of the 30 primary caregivers 6 (20%) experienced lower burden (score < 80 on BAS) whereas the rest 24 (80%) experienced higher burden (score > 80 on BAS). Caregivers with lower burden in Schizophrenia resorted to coping strategies like Positive cognitive, Negative cognitive, Problem solving, Distraction and External Attribution significantly more than the caregivers with higher burden. On the other hand those with higher burden used coping strategies like Magical Thinking and religious coping significantly more than those with lower burden. A positive correlation was found between caregiver's burden and level of impairment in functioning of patients of Chronic Schizophrenia. **Conclusion:** Coping mechanisms like cognitive coping, problem solving, distraction and external attribution can decrease the burden of illness. Therefore their analysis is essential, before clinical interventions, to improve the coping skill of the caregiver.

**Keywords:** Schizophrenia, Burden, Coping, Caregiver

## 1. Introduction

Schizophrenia is the paradigmatic illness of psychiatry. The policy of de-institutionalization has highlighted the role of family members as the primary source of care giving for relatives with schizophrenia. A noteworthy finding by Weidman et al<sup>[1]</sup> was that despite the apparent downfall of traditional family structure, over 60% of patients with long term schizophrenia live with at least one 'significant other' i.e. Primary Caregiver. In India, families are always recognised as an integral part of the care system for persons with chronic mental illness, such as schizophrenia. The demands of being involved in the care of a seriously mentally ill relative have both an emotional as well as practical impact on the caregiver.<sup>[2, 3]</sup>

The costs that families incur in terms of economic hardships, social isolation and psychological strain, are referred to as family burden<sup>[4-6]</sup>. The fact that the illness leaves a varying degree of disability in the patient and leads to disturbing behaviour means that its management is associated with a significant burden of care. As a result of the paucity of organised care, families have been part of mental health care all throughout the history of India. In addition there is also evidence to suggest that family involvement in patient-care continues to be preference of families and thus family members serve as the main source of support for schizophrenic individuals. All the relatives do not necessarily behave in the same manner and the nature of the burden placed on them may possibly lead some to resort to ineffective coping strategies. It has been observed that for a

given amount of burden, the individual level of distress show considerable variations<sup>[7]</sup>, because it varies according to their ways of coping. Folkman and Lazarus<sup>[8, 9]</sup> have defined coping as a person's constantly changing cognitive and behavioural efforts to manage an encounter appraised as stressful.

The relationship between coping styles and perceived burden of care is complex because caregivers subjectively report 'burden'. This subjectivity in turn is a product of the coping styles used by the caregivers. Pai and Kapur<sup>[10]</sup> observed that in view of the economic and cultural conditions of a developing country being vastly different from those of the western world, the areas of burden and the pattern of accepting or rejecting patients in India may be entirely different. Several patient and caregiver variables have been found to contribute to family burden. Greater burden is associated with patient who are male<sup>[11, 12]</sup>, younger in age<sup>[13, 14]</sup> and who have poorer levels of functioning<sup>[15, 16]</sup>. Caregiver characteristics associated with burden have received comparatively less attention. Women take on a large part of care giving responsibilities<sup>[17]</sup> and caregivers who are younger and more educated experience greater burden<sup>[18]</sup>. The relationship of the primary caregiver to the patient may also mediate the experience of burden.

**Burden** refers to the presence of problems, difficulties or adverse events which affects the lives of individuals who are primary carers of persons with mental health problems. Numerous definitions of burden exist in literature and these share a common underlying frame of reference, namely the

effect of the patient on the family<sup>[19]</sup>; impact of living with a psychiatric patient on the way of life and health of family members or the difficulties felt by the family of a psychiatric patient<sup>[5]</sup>. **Platt (1985)**<sup>[7]</sup> defined burden as “the presence of problems, difficulties or adverse events that affect the lives of psychiatric patients”. **Hoeing and Hamilton** in the late 1960s were the firsts to make a clear distinction between subjective and objective aspects of burden. ‘Objective burden’ is used to identify anything that occurs as a disrupting factor in family life owing to the patient’s illness. ‘Subjective burden’ refers to the feeling that the burden is being carried in a subjective sense or the extent to which relatives felt they carried a burden. Of the family members, the consequences of caring is high in the life of a family member who bears maximum responsibility.<sup>[34]</sup>

In 1955, **Clausen and Yarrow**<sup>[20]</sup> led a group of social scientists of the United States to carry out the first study on the demands of the families of the mental patients. In Indian context, **Pai and Kapur** in 1981<sup>[5]</sup> described six areas of burden: financial burden, effect on family routine, effect on family leisure, effect on family interaction, effects on physical health of other family members and effect on mental health of other family members.

**Thara in 1998**<sup>[21]</sup> developed a burden assessment schedule, which is a 40 item scale measuring different areas similar to as mentioned by Pai and Kapur. In addition, it contains items that tap areas of emotional burden specific to spouses, such as the effect of the illness on the patient’s ability to share responsibilities, sexual relations and the overall quality of the marital relationship. **Singh et al. 2012**<sup>[22]</sup> in his study ‘**Burden of schizophrenia on caregivers in Nepal**’ reported that most burden was in the area of finance and family dynamics and overall burden was moderate. **Gupta et al. 2014**<sup>[23]</sup> found that 80% of the caregivers have experienced moderate levels of burden. Older caregivers experienced higher burden whereas gender and educational status exerted no significant effect on burden. The burden was significantly higher among spouses followed by parents, and the level of burden was positively correlated to the duration of care.

**Pearlin and Schooler**<sup>[24]</sup> defined coping as the cognitive and behavioural effort made to master, tolerate or reduce demands that tax or exceed a person’s resources. Freud (1946)<sup>[25]</sup> and Haan (1977)<sup>[26]</sup> viewed coping and defence through psychoanalytic conception or largely unconscious responses to internal conflicts. Coping has been conceptualized in terms of approach vs. avoidance<sup>[27]</sup> and in terms of appraisal; problem focus and emotion focus<sup>[28]</sup>.

Care giving is a chronic stressor and different coping methods are used to handle such a situation. The use of coping strategies such as avoidance, denial and resignation is linked to greater burden<sup>[29, 30]</sup> whereas utilization of social support and a sense of mastery over the situation are associated with lower level of burden and distress<sup>[31]</sup>.

In 1994, the consensus reported by **Troop**<sup>[32]</sup> states that emotion based coping is associated with an unsatisfactory outcome whereas problem focused coping is associated with a more satisfactory outcome. Spouses reported greater

emotional burden<sup>[33]</sup>. Parents used more of denial as a coping strategy, while spouses used more of negative distraction strategies. On stepwise regression analysis, patient’s age, educational level, and level of functioning and caregiver’s use of denial as a coping strategy emerged as significant predictors of caregiver burden. The study highlights the fact that family intervention programs need to address the specific concerns of caregivers. **Batra et al. 2015**<sup>[35]</sup> in their study found that majority of the caregivers were male and parents above the age 50 yrs. Majority of the caregivers were non literate and unemployed. Most of the caregivers used ‘seeking spiritual support’ as the strongest coping strategy and ‘mobilizing family to accept help’ as the weakest coping strategy. There was no association found between the selected demographic variable and the caregivers’ coping strategies. The present study is an attempt to assess these areas of burden and coping in families of patients of chronic schizophrenia.

#### **Aim and objectives:**

- 1) To assess burden of Caregiver of Chronic Schizophrenia.
- 2) To assess coping strategies adopted by the Caregivers of Chronic Schizophrenia.
- 3) To study the relationship of burden and coping strategies in Caregivers of Chronic Schizophrenia.
- 4) To assess the relationship of burden of the caregiver with the global assessment of functioning of Chronic Schizophrenic patients.

## **2. Materials and Methods**

- a) **Study sample:** Sample was randomly selected from the Caregivers of Chronic Schizophrenic in-patients and out-patients of Department of Psychiatry, Assam Medical College and Hospital, Dibrugarh.
- b) **Sample size:** Primary Caregiver of 30 Chronic Schizophrenic patients.
- c) **Study design:** Hospital Based Cross sectional study.
- d) **Duration of study:** One year
- e) **Definition of Primary Caregiver** – A person who is currently shouldering maximum responsibility and care of the patient in terms of social, physical, emotional and financial support for a considerable period of two years or more.

Inclusion and exclusion criteria:

#### **Inclusion criteria:**

##### **a) For the patient –**

- Age 18 years and above (either sex)
- Diagnosed case of Schizophrenia according to ICD-10 without any co-morbid psychiatric disorder
- Duration of illness, two years and above at the time of examination

##### **b) For the caregiver –**

- Healthy adult family members staying currently with the patient and for previous two years of illness

#### **Exclusion criteria**

##### **a) For the patient –**

- Those with co-morbid major physical illness like diabetes, hypertension, carcinoma etc.

- Mental Retardation.
- Substance dependence.
- Absent from home for a period of 6 months or more.

**b)For the caregiver –**

- Those with psychiatric illness were excluded.

**Tools:**

- **Burden Assessment Schedule (Thara, 1998)** [21]: The Burden Assessment Schedule (BAS, 98) developed by Thara et al, at the Schizophrenia Research Foundation is based on the principle of ‘stepwise ethnographic exploration’ described by Sell and Nagpal in 1992. This is a semi-quantitative, 40 items scale measuring 9 different areas of subjective and objective caregiver burden. In BAS the minimum score is 40 and the maximum score is 120.
- **Coping checklist (Rao and Prabhu, 1989)** [36]: This scale comprises of 70 items describing a broad range of behavioural, emotional and cognitive responses that may be used to handle stress. Items are scored as Yes or No. This scale is reported to be useful in both clinical and research settings especially within the stress coping social support framework on the basis of the type of questions.
- **Global Assessment of Functioning Scale (GAF)** – the GAF scale is a measure of rating the overall psychological, social and occupational functioning of the patient, first included in DSM –III-R as Axis V of the multi axial diagnostic system. It is a modified version of “The Global Assessment Scale” developed by Endicott et al in 1976. The scale has 10 ranges of functioning where each range has two components covering symptom severity and patient functioning.
- **Socio demographic details** of both the patients and caregivers were recorded on a proforma designed to collect the following details in addition to the age, sex, education, socio-economic status, family type and domiciliary status – the type of diagnosis and duration of illness of the patients. The proforma also includes caregiver details, mentioning the relationship to the patient and the duration of care.

Procedure: Study subjects were thoroughly evaluated on the basis of history and mental status examination. Diagnosis of Schizophrenia was done as per guidelines listed in ICD-10 and confirmed by senior psychiatrist. Patients and their primary caregiver who fulfil the inclusion criteria and did not meet the exclusion criteria were selected. Written Informed consent was taken from each of the Caregivers before including them in the study. Proforma for socio demographic data was filled up for socio-demographic details of patients and their primary caregivers. Global assessment of functioning was applied to all patients. Burden Assessment Schedule and Coping Checklist were applied to all primary caregivers and scoring done. Appropriate statistical test in MS Excel were applied to analyze the obtained data setting the significance threshold at p<0.05.

**3. Results and Observations**

In the present study 30 schizophrenic patients participated out of whom 50% were in the age range of 18-30 years with the mean age being 33.7±11.62 years. Prevalence was more among male with male to female ratio being 2.3:1. The prevalence of the disease was significantly higher in the rural areas. Majority of the patients were unmarried (60%), belonged to nuclear families (70%), unemployed (53.3%), educated upto middle education level (53.3%) and belonged to poorer families with family income of less than 2040 Rs/month (43.3%). Majority had duration of illness between 2-5 years followed by patients with duration 10 or more than 10 years.

**Table 1: Socio-Demographic Characteristics of Patients**

| Patient Variable  | Variable subgroup  | Schizophrenia |       |
|-------------------|--------------------|---------------|-------|
|                   |                    | No            | (%)   |
| Age (years)       | 18-30              | 15            | 50.00 |
|                   | 31-43              | 7             | 23.33 |
|                   | 44-56              | 7             | 23.33 |
|                   | >56                | 1             | 3.33  |
| Sex               | Male               | 21            | 70.00 |
|                   | Female             | 9             | 30.00 |
| Religion          | Hindu              | 27            | 90.00 |
|                   | Muslim             | 3             | 10.00 |
| Locality          | Urban              | 6             | 20.00 |
|                   | Rural              | 24            | 80.00 |
| Marital status    | Unmarried          | 18            | 60.00 |
|                   | Married            | 12            | 40.00 |
| Family type       | Nuclear            | 21            | 70.00 |
|                   | Joint              | 9             | 30.00 |
| Employment status | Unemployed         | 16            | 53.30 |
|                   | Full time employed | 3             | 10.00 |
|                   | Part time employed | 0             | 0.00  |
|                   | Self employed      | 6             | 20.00 |
|                   | Student            | 1             | 3.33  |
|                   | Housewife          | 4             | 13.33 |
| Family income     | <2,040             | 13            | 43.33 |
|                   | 2,041-6,100        | 13            | 43.33 |
|                   | 6,101-10,160       | 4             | 13.33 |
|                   | 10,161-15,280      | 0             | 0.00  |
|                   | 15,281-20,360      | 0             | 0.00  |
| Education         | Illiterate         | 3             | 10.00 |
|                   | Literate           | 0             | 0.00  |
|                   | Primary education  | 4             | 13.33 |
|                   | Middle education   | 16            | 53.33 |
|                   | Matriculation/H.S  | 5             | 16.66 |
|                   | Graduate           | 2             | 6.66  |

**Table 2: Distribution according to duration of illness**

| Duration of illness (in years) | Schizophrenia |      |
|--------------------------------|---------------|------|
|                                | No            | (%)  |
| 2-5                            | 14            | 46.7 |
| 6-9                            | 6             | 20.0 |
| Equal to or more than 10       | 10            | 33.3 |

Table 3 shows that 50% of the schizophrenic patients had functioning score between 31-40 followed by 36.6% of patients with functioning score of 41-50.

**Table 3:** Distribution according to global assessment of functioning (GAF) score of patients

| GAF score | Schizophrenia |      |
|-----------|---------------|------|
|           | No            | %    |
| 21-30     | 2             | 6.7  |
| 31-40     | 15            | 50.0 |
| 41-50     | 11            | 36.6 |
| 51-60     | 2             | 6.7  |
| 61-70     | 0             | 0.0  |
| 71-80     | 0             | 0.0  |

**Table 4:** Distribution of caregivers according to socio-demographic characteristics

| Caregiver variable      | Sub-variable       | Schizophrenia |       |
|-------------------------|--------------------|---------------|-------|
|                         |                    | no            | (%)   |
| Age                     | 18-30              | 7             | 23.33 |
|                         | 31-43              | 10            | 33.33 |
|                         | 44-56              | 5             | 16.67 |
|                         | >56                | 8             | 26.67 |
| Sex                     | Male               | 14            | 46.67 |
|                         | Female             | 16            | 53.33 |
| Marital status          | Unmarried          | 8             | 26.67 |
|                         | Married            | 22            | 73.33 |
| Employment              | Unemployed         | 4             | 13.33 |
|                         | Full time employed | 4             | 13.33 |
|                         | Part time employed | 1             | 3.33  |
|                         | Self employed      | 8             | 26.67 |
|                         | Student            | 0             | 0.00  |
|                         | Housewife          | 12            | 40.00 |
|                         | Others             | 1             | 3.33  |
|                         |                    |               |       |
| Education               | Illiterate         | 5             | 16.67 |
|                         | Literate           | 2             | 6.67  |
|                         | Primary education  | 5             | 16.67 |
|                         | Middle education   | 8             | 26.67 |
|                         | Matriculation/H.S  | 7             | 23.33 |
|                         | Graduate           | 3             | 10.00 |
| Family income           | <2,040             | 13            | 43.33 |
|                         | 2,041-6,100        | 13            | 43.33 |
|                         | 6,101-10,160       | 4             | 13.33 |
|                         | 10,161-15,280      | 0             | 0.00  |
|                         | 15,281-20,360      | 0             | 0.00  |
| Relationship to patient | Spouse             | 5             | 16.67 |
|                         | Parent             | 13            | 43.33 |
|                         | Sibling            | 8             | 26.67 |
|                         | Children           | 2             | 6.67  |
|                         | Others             | 2             | 6.67  |
|                         |                    |               |       |

Majority of caregivers were in the age range of 31-43 years followed by >56 year age group. Mean age of caregivers was 44.03±15.56. Majority were female (53.3%), married (73.33%), housewives (40%), educated upto middle education level and belonged to poorer families. Parents constituted the predominant population among the caregivers followed by siblings and spouses.

Most common coping styles used were religious coping (90%) followed by help seeking (86.67%) and external attribution (86.67%).

Among the caregivers older people (>56yrs) tended to have more family burden with mean score 103.25±35.28. Mean Burden Assessment Score (BAS) were more for female caregivers than males and more among those who were married, illiterate, spouses and those who belonged to poorer families.

**Table 5:** Distribution of caregivers according to duration of care

| Duration of Care (in years) | Schizophrenia |       |
|-----------------------------|---------------|-------|
|                             | No            | (%)   |
| 2-5                         | 14            | 46.67 |
| 6-9                         | 8             | 26.67 |
| Equal to or more than 10    | 8             | 26.67 |

**Table 6:** Distribution of caregivers according to total burden assessment schedule (BAS) score

| Total BAS score | Schizophrenia |       |
|-----------------|---------------|-------|
|                 | No            | (%)   |
| <80             | 6             | 20.00 |
| >80             | 24            | 80.00 |

**Table 7:** Different types of coping used by caregivers of Schizophrenia

| Coping style         | Used/Not used | Schizophrenia |       |
|----------------------|---------------|---------------|-------|
|                      |               | No            | (%)   |
| Positive cognitive   | Used          | 24            | 80.00 |
|                      | Not used      | 6             | 20.00 |
| Negative cognitive   | Used          | 21            | 70.00 |
|                      | Not used      | 9             | 30.00 |
| Problem solving      | Used          | 25            | 83.33 |
|                      | Not used      | 5             | 16.67 |
| Magical thinking     | Used          | 25            | 83.33 |
|                      | Not used      | 5             | 16.67 |
| Avoidance            | Used          | 5             | 16.67 |
|                      | Not used      | 25            | 83.33 |
| Distraction          | Used          | 18            | 60.00 |
|                      | Not used      | 12            | 40.00 |
| Religious            | Used          | 27            | 90.00 |
|                      | Not used      | 3             | 10.00 |
| Help seeking         | Used          | 26            | 86.67 |
|                      | Not used      | 4             | 13.33 |
| External attribution | Used          | 26            | 86.67 |
|                      | Not used      | 4             | 13.33 |

**Table 8:** Comparison of burden with coping in schizophrenia caregivers

| COPING               | GROUP A<br>(Burden <80)<br>(n = 6) |       | GROUP B<br>(Burden >80)<br>(n = 24) |       | P value  |
|----------------------|------------------------------------|-------|-------------------------------------|-------|----------|
|                      | Mean                               | SD    | Mean                                | SD    |          |
|                      | Positive cognitive                 | 24.00 | 5.87                                | 17.00 |          |
| Negative cognitive   | 10.50                              | 0.85  | 4.87                                | 0.51  | <0.0001* |
| Problem solving      | 25.00                              | 6.01  | 19.79                               | 3.85  | 0.0132*  |
| Distraction          | 12.00                              | 1.03  | 9.75                                | 0.78  | <0.0001* |
| Magical thinking     | 16.60                              | 2.12  | 20.80                               | 4.04  | 0.0212*  |
| Avoidance            | 0.83                               | 0.04  | 0.83                                | 0.04  | 1.000    |
| Religious            | 13.50                              | 1.52  | 25.80                               | 6.19  | <0.0001* |
| Help seeking         | 21.60                              | 4.89  | 20.58                               | 4.00  | 0.5965   |
| External attribution | 26.00                              | 6.59  | 20.58                               | 4.00  | 0.0148*  |

[\*: p value Significant at <0.05]

Table 8 shows that the caregivers with lower burden in schizophrenia had resorted to coping strategies like Positive cognitive, Negative cognitive, Problem solving, Distraction and External Attribution significantly more than the caregivers with higher burden. On the other hand those with higher burden used coping strategies like Magical Thinking and Religious coping significantly more than those with lower burden. There was no significant difference in the use of coping strategies like avoidance and help seeking between the two groups.



**Table 9:** Correlation between Global Assessment of Functioning (GAF) of patients with burden of caregiver in Chronic Schizophrenia

| Total GAF Score | CAREGIVER OF SCHIZOPHRENIA |       | “r” Value  |
|-----------------|----------------------------|-------|------------|
|                 | Mean BAS score             | SD    |            |
| 21-30           | 109.50                     | 37.25 | r = 0.9783 |
| 31-40           | 95.20                      | 25.15 |            |
| 41-50           | 93.18                      | 24.02 |            |
| 51-60           | 101.00                     | 34.83 |            |
| 61-70           | 0.00                       | 0     |            |
| 71-80           | 0.00                       | 0     |            |

Table 9 shows a “r” value of 0.9783, which is closer to 1.00, indicating high positive correlation between caregiver’s burden and level of impairment in functioning of schizophrenic patients.

#### 4. Discussion

Majority of the patients were male in the age range of 18-30 years, single, unemployed and belonged to low income families of rural background. This is consistent with the findings of Gopinath and Chaturvedi in 1992, Karno and Norquist in 1989<sup>[18, 37]</sup>. Majority of the caregivers were in the age range of 31-43, females, married, educated up to middle education level and belonged to low income families. Our findings are in line with the findings of Jenkins and Schumacker in 1999, who found that women take on a large part of care giving responsibility. Parents constituted the predominant population among the caregivers. Positive correlation was found between the caregiver’s burden of illness and patient’s impairment in functioning. Our findings are in accordance with the findings of Gautam and Nijhawan in 1984, Roy Choudhury et al. 1995; and Credo and Parkar in 2006<sup>[11,14,38]</sup>. Those caregivers who had lower burden most commonly used problem solving coping than the higher burden group who used more of religious and magical thinking as coping strategies. This finding is in keeping with the findings of Credo and Parker in 2006, Sczufca and Kuipers in 1999 and Chandrasekaran et al. 2002.<sup>[38-40]</sup>

#### 5. Conclusion

Thus as the patient’s impairment in functioning increases, burden of illness also increases. Most caregivers used religious coping followed by external attribution and magical thinking. Caregivers with lower burden most commonly used problem solving coping strategies while those with higher burden used more of religious coping and magical thinking as coping strategies. It was also seen those with lower burden used coping mechanisms like Positive coping, Negative coping, Distraction, Problem solving and External Attribution significantly more than those with higher burden. On the other hand those with higher burden used coping strategies like magical thinking and religious coping significantly more than those with lower burden.

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