

A STUDY OF BURDEN OF CAREGIVERS OF SCHIZOPHRENIA PATIENTS WITH REGARDS TO CERTAIN DEMOGRAPHIC VARIABLES

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ABSTRACT : *The main aim of the present research was to study the burden among the caregivers of schizophrenic patients. Total sample of 120 caregivers of schizophrenic patients were taken randomly from a tertiary care teaching hospital psychiatry department in Vadodara. The Zarit Burden Interview (ZBI) schedule was used to collect data. After taking written informed consent the tool was administered in individual setting. On completion of the data collection responses of each respondent on ZBI were scored as per the scoring key of its manual. Data analysis was done by applying 't' test. On analysis of data of 120 respondents, it was found that female caregivers have more burden than male caregivers, urban caregivers have more burden than rural caregivers, caregivers of nuclear family have more burden than caregivers of joint family, caregivers of lower socio economic status have more burden than caregivers of higher socio economic status, caregivers of below graduate have more burden than caregivers of above graduate. Significant difference did not exist between employed and unemployed caregivers of schizophrenic patients with regard to burden, significant difference also does not exist between spouse and parents of schizophrenic patients with regards to burden. The burden of care on caregivers of schizophrenia patients is severe and should be addressed on an ongoing basis for better outcome of illness.*

Key Words: Burden of Care, ZBI, Schizophrenia.

Introduction : Schizophrenia is a psychotic disorder (or group of disorders) marked by schism of thinking, emotions, and behaviors. The term Schizophrenia comes from two Greek words – Schizo means split and phrenia means mind. It was coined around 1908 by a Swiss doctor named Eugen Bleuler to describe the splitting apart of mental functions that he regarded as the central characteristic of Schizophrenia.

Schizophrenic patients are typically unable to sort sensory stimuli and may have enhanced perceptions of sounds, colors, and other features of their environment. Most Schizophrenics, if untreated, gradually withdraw from interactions with other people, and lose their ability to take care of personal needs and grooming. The course of Schizophrenia in adults can be divided into three phases or stages.

- In the acute phase, the patient has an overt loss of contact with reality (psychotic episode) that requires intervention and treatment.
- In the second or stabilization phase, the initial psychotic symptoms have been brought under control but the patient is at risk for relapse if treatment is interrupted.
- In the third or maintenance phase, the patient is relatively stable and can be kept indefinitely on antipsychotic medications.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), to be diagnosed with Schizophrenia, three diagnostic criteria must be met.

1. Characteristic symptoms: Two or more of the following, each present for much of the time during a one-month period (or less, if symptoms remitted with treatment).

- Delusions
- Hallucinations
- Disorganized speech, which is a manifestation of formal thought disorder
- Grossly disorganized behavior (e.g. dressing inappropriately, crying frequently) or catatonic behavior
- Negative symptoms— affective flattening (lack or decline in emotional response), alogia (lack or decline in speech), or avolition (lack or decline in motivation)

2. Impairment in one of the major areas of functioning for a significant period of time since the onset of the disturbance: Work, interpersonal relations, or self-care.

3. Some signs of the disorder must last for a continuous period of at least 6 months. This six-month period must include at least one month of symptoms (or less if treated) that meet criterion A (active phase symptoms) and may include periods of residual symptoms. During residual periods, only negative symptoms may be present.

4. Schizoaffective disorder and bipolar or depressive disorder with psychotic features have been ruled out.
5. No major depressive or manic episodes occurred concurrently with active phase symptoms.
6. If mood episodes (depressive or manic) have occurred during active phase symptoms, they have been present for a minority of the total duration of the active and residual phases of the illness.
7. The disturbance is not caused by the effects of a substance or another medical condition
8. If there is a history of autism spectrum disorder or a communication disorder (childhood onset), the diagnosis of schizophrenia is only made if prominent delusions or hallucinations, along with other symptoms, are present for at least one month.

Family has been an essential part of mental health care programmes in India for a long time. This is in contrast to the emphasis on professionals and institutions in mental health care in the developed countries (Shankar 1998, Srinivasa Murthy 2000). Where the state has taken the prime responsibility for the mentally ill. A study conducted by the Canadian Alliance for Research on Schizophrenia to "evaluate the concrete and complex interactions of specific families in order to identify the positive attributes which could in turn, predict improved outcome". The research staff interviewed 29 parents from 19 middle or working class families, many of whom were retired. The interviewed parents had 6 daughters and 14 sons diagnosed with Schizophrenia. They were asked broad, open-ended questions to elicit both the positive and negative consequences of caring for the family member with Schizophrenia. Most of the parents reported that they felt 'disenfranchised' as they met many obstacles when they tried to intervene on behalf of the adult children. Most of them reported that professionals did not answer their questions and did not value their opinions about the illness of their children. Also the professionals did not respect their interventions and that made them feel helpless. Thus the state has taken over too much responsibility and the families are left to provide lifelong care to their ill member without having the right to decide the best course of action for them.

Caregivers face problems of coping with the social withdrawal, behaviours and disruptive attitude of patients with Schizophrenia. These behaviours may be unhealthy for the caregivers and may create a lot of stress and emotional discomfort. Severe mental illness, like Schizophrenia, has far-reaching consequences for both patients and their relatives (Hatfield and Lefley, 1987).

Patients' relatives experience feelings of loss and grief (Miller et al. 1990). They are confronted with uncertainty and emotions of shame, guilt, and anger. Like the patient, they feel stigmatized and socially isolated (Wahl and Harman 1989). Their lives may be disrupted by providing more care than would normally be appropriate for someone of the patient's age. In those cases where reciprocity between family members is out of balance, normal care changes into Caregiving. Addition of the Caregiving role to already existing family roles may become stressful, both psychologically and economically (Clark 1994; Schene et al. 1996).

A study with 307 Schizophrenia patients in Leipzig, Germany, revealed that 32.9 percent of the subjects were married or were living with a partner (Kilian et al. 2001). Apparently, female patients suffering from Schizophrenia have better chances of marrying or having a stable partnership than their male counterparts (Stromwall and Robinson 1998; Hafner and Heiden 1997).

Besides, it is remarkable that patients permanently living with a spouse have an exceedingly positive illness and social prognosis (Schulze Monkling et al. 1996; Salokangas 1997). This finding suggests that patients with a relatively favorable course of illness are more likely to find a spouse and to maintain their partnership; it also appears plausible that an intact partnership represents a protective factor for the patients' long-term coping with the illness. As Salokangas (1997) has pointed out in this context, Review of Literature 56 positive interactions between the stability of the partnership and the course of the illness, as well as with the coping process, are likely.

Hell's study (1982) yielded that spouses of Schizophrenia patients and spouses of depressive patients do not differ regarding their personality structure, neither within their groups nor in comparison to the general population. Illness-specific patterns of relationships (e.g., "typical schizophrenic" relationships) also could not be identified. In both subsamples, the course of the illness is accompanied by adaptation processes on the part of the spouses that have a normalizing and stabilizing effect on the partnership.

Ivarsson et al. (2004) contend that family caregiver burden is complex and includes several areas such as activities in daily life, worry and social strain. Effective family functioning in families with schizophrenia may be influenced by a variety of psychosocial factors (Saunders, 2003). Family conflict and family intimacy have been found to reflect the degree of burden or reward experienced and it is suggested that the family system, as the context within which the patient exists, be seen as the mediating environment for caregiving burden and reward (Heru, 2000).

Winefield and Harvey (1993) found that caregiver psychological distress was high and the level of behavioral disturbance in the sufferer was found to contribute to caregiver distress after controlling for the caregiver's age, sex, and social supports. In general, changes in the parents' burden level are closely interconnected with the illness curve of the patients, and Jungbauer et al. (2003), observe that parents of continuously and severely affected patients are overloaded with their long-term caring tasks. It is also seen that parents and spouses perceive the caregiver burden differently, although there are some apparent similarities (Lauber et al., 2003).

Jungbauer et al. (2004), hold that the spouses not only face illness-specific burdens but also burdens resulting from their partnership and family roles. The chronic burden of everyday living can profoundly reduce the quality of life and the subject's satisfaction with the partnership.

Objectives:

1. To assess burden between male and female caregivers of patients suffering from schizophrenia.
2. To assess burden between urban and rural caregivers of patients suffering from schizophrenia.
3. To assess burden between joint and nuclear family caregivers of patients suffering from schizophrenia.
4. To assess burden between higher Socio economic status and lower Socio economic status of caregivers of patients suffering from schizophrenia.
5. To assess burden among below and above graduate caregivers of patients suffering from schizophrenia.
6. To assess burden between employed and unemployed caregivers of patients suffering from schizophrenia.
7. To assess burden between spouse and parents caregivers of patients suffering from schizophrenia.

Hypothesis:

1. There will be no significant difference between male and female caregivers of patients suffering from schizophrenia with regards to burden.
2. There will be no significant difference between urban and rural caregivers of patients suffering from schizophrenia with regards to burden.
3. There will be no significant difference between joint and nuclear family caregivers of patients suffering from schizophrenia with regards to burden.
4. There will be no significant difference between higher Socio economic status and lower Socio economic status caregivers of patients suffering from schizophrenia with regards to burden.
5. There will be no significant difference between below and above graduate caregivers of patients suffering from schizophrenia with regards to burden.
6. There will be no significant difference between employee and unemployed caregivers of patients suffering from schizophrenia with regards to burden.
7. There will be no significant difference between spouse and parents caregivers of patients suffering from schizophrenia with regards to burden.

Sample:

Total sample of 120 caregivers of schizophrenic patients were taken randomly from a tertiary care teaching hospital psychiatry department in Vadodara.

Variables:

In present research gender, area of residence, type of family, socio economic status, level of education, occupation and relatives were considered as independent variable and scores of Zarit Burden Interview scheduled was considered as dependent variable.

Tool:

In present research for the data collection Zarit Burden Interview (ZBI) scheduled was used. This is a 22-item instrument that includes the items most frequently mentioned by caregivers as problem areas in providing care for patients with chronic mental illness. The ZBI explores the negative physical, mental, social, and economic impacts of caregiving on the life of the caregiver. The responses are rated on a Likert scale of 0 (never) to 4 (almost always) with a total score of 0–88. Higher scores indicate higher levels of caregiver burden or distress. The instrument has been widely used to assess caregiver burden on family members of patients with schizophrenia in Asia, South America, and Africa.

Procedure:

After establishing the rapport with respondents above mentioned tool was administered in individual setting. After completion of the data collection, responses of each respondent on Zarit Burden Interview Schedule were scored as per the scoring key of Zarit Burden Interview schedule.

Statistical Analysis:

To analyze the data t test was used. Each hypothesis was tested at 0.01 level and 0.05 significant level. Data was analyzed with help of statistical package for social sciences (SPSS).

Result and Discussions:

Table No. 1

Sowing mean, SD and t value of male and female caregivers of patients of suffering from schizophrenia

Group	N	Mean	SD	t value	Level of significant
Male	66	41.67	16.54	2.65	0.01
Female	54	49.31	15.05		

Table no.1 shows the mean scores of male and female caregivers of schizophrenic patients on burden is 41.67 and 49.31 respectively with SD 16.54 and 15.05. The t value of burden is 2.65 which is significant at 0.01 level. It indicates that significant difference exist between male and female caregivers of schizophrenic patients. Female caregivers of schizophrenic patients have more burden than male caregivers of schizophrenic patients.

Table No. 2

Sowing mean, SD and t value of urban and rural area caregivers of patients suffering from schizophrenia

Group	N	Mean	SD	t value	Level of significant
Urban	71	41.14	16.06	3.39	0.01
Rural	49	50.86	14.97		

Table no.2 shows the mean scores of urban and rural caregivers of schizophrenic patients on burden is 41.14 and 50.86 respectively with SD 16.06 and 14.97. The t value of burden is 3.39 which is significant at 0.01 level. It indicates that significant difference exist between urban and rural caregivers of schizophrenic patients. Rural caregivers of schizophrenic patients have more burden than urban caregivers of schizophrenic patients.

Table No. 3

Sowing mean, SD and t value of joint and nuclear family caregivers of patients of suffering from schizophrenia

variable	N	Mean	SD	t value	Level of significant
Joint	42	42.81	17.49	1.10	NS
Nuclear	78	46.35	15.54		

Table no.3 shows the mean scores of joint and nuclear family caregivers of schizophrenic patients on burden is 42.81 and 46.35 respectively with SD 17.49 and 15.54. The t value of burden is 1.10 which is not significant. It indicates that significant difference does not exist between joint and nuclear family of caregiver's schizophrenic patients.

Table No. 4

Sowing mean, SD and t value of higher socio economic status and lower high socio economic status caregivers of patients of suffering from schizophrenia

variable	N	Mean	SD	t value	Level of significant
Higher SES	43	38.23	16.43	3.54	0.01
Lower SES	77	48.95	14.97		

Table no.4 shows the mean scores of lower and higher socio economic status caregivers of schizophrenic patients on burden is 38.23 and 48.95 respectively with SD 16.43 and 14.97. The t value of burden is 3.54 which is significant at 0.01 level. It indicates that significant difference exist between Higher SES and Lower SES lower and higher caregivers of schizophrenic patients on burden. Lower socio economic status caregivers of schizophrenic patients have more burden than higher socio economic status caregivers of schizophrenic patients.

Table No. 5

Sowing mean, SD and t value of below graduate and above graduate caregivers of patients of suffering from schizophrenia

variable	N	Mean	SD	t value	Level of significant
Above Graduate	22	34.18	17.96	2.26	0.05
Below Graduate	60	43.15	15.43		

Table no.5 shows the mean scores of below graduate and above graduate caregivers of schizophrenic patients on burden is 34.18 and 43.15 respectively with SD 17.96 and 15.43. The t value of burden is 2.26 which is significant at 0.01 level. It indicates that significant difference exist between below and above graduate caregivers schizophrenic patients. Below graduate caregivers of schizophrenic patients have more burden than above graduate caregivers of schizophrenic patients.

Table No. 6

Sowing mean, SD and t value of employed and unemployed caregivers of patients of suffering from schizophrenia

variable	N	Mean	SD	t value	Level of significant
Employed	76	45.05	17.23	0.01	N.S.
Unemployed	43	45.07	14.80		

Table no.6 shows the mean scores of employed and unemployed caregivers of schizophrenic patients on burden is 45.05 and 45.07 respectively with SD 17.23 and 14.80. The t value of burden is 0.01 which is not significant. It indicates that significant difference does not exist between employee and unemployed caregivers schizophrenic patients.

Table No. 7

Sowing mean, SD and t value of Spouse and Parents caregivers of patients of suffering from schizophrenia

variable	N	Mean	SD	t value	Level of significant
Spouse	48	48.00	13.38	0.06	N.S.
Parents	53	47.83	16.17		

Table no.7 shows the mean scores of spouse and parents caregivers of schizophrenic patients on burden is 48.00 and 47.83 respectively with SD 13.38 and 16.17. The t value of burden is 0.06 which is not significant. It indicates that significant difference does not exist between spouse and parents caregivers schizophrenic patients.

Conclusions:

1. Significant difference exists between male and female caregivers of schizophrenic patients on burden. Female caregivers have more burden than male caregivers of schizophrenic patients on burden.
2. Significant difference exists between urban and rural caregivers of schizophrenic patients on burden. Urban caregivers have more burden than rural caregivers of schizophrenic patients on burden.
3. Significant difference does not exist between joint and nuclear family caregivers of schizophrenic patients with regards to burden.
4. Significant difference exists between higher socio economic status and lower socio economic status caregivers of schizophrenic patients on burden. Caregivers of lower socio economic status have more burden than caregivers of higher socio economic status,
5. Significant difference exists between below graduate and above graduate caregivers of schizophrenic patients on burden. Caregivers of below graduate have more burden than caregivers of above graduate.
6. significant difference does not exist between employee and unemployed caregivers of schizophrenic patients with regard to burden
7. Significant difference also does not exist between spouse and parents of schizophrenic patients with regards to burden.

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