

Caregiver Burden and Psychopathology in Schizophrenia : A Cross Sectional Study

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ABSTRACT

Introduction: In developing countries like India where there is dearth of resources, major share and burden of caretaking of mentally ill patients is taken up by family members. Although lot of literature is available on caregiver burden and its correlates, there is only limited literature on caregiver burden in relation to various stages of schizophrenia and its implications. Our study was conducted to bridge this gap.

Material and Methods: A cross-sectional study of sixty chronic schizophrenia patients admitted to IMH, Hyderabad from January 2015 to April 2015, were studied along with their primary caregivers. Burden Assessment Schedule (BAS), Positive and Negative Syndrome Scale (PANSS) were the scales used.

Results: Negative symptoms were found to be better correlated with caregiver burden than positive or general psychopathology scores ($R = 0.39$, $p = 0.0019$). The implications of this finding were discussed.

Conclusion: Chronic stage is characterised by predominant negative symptoms and consequently high caregiver burden. Thus, different interventions are needed for both patients and caregivers in different stages.

Keywords: Care giver burden, schizophrenia, BAS, PANSS

INTRODUCTION

In the early psychiatric literature, the family of the patient was often looked upon as a source of the mental illness. But the perspective has now changed to incorporate the family as a "reactor" to mental illness of its member. ^[1] With further advances in the treatment of mental disorders, we recognized the usefulness of the family in the care of the mentally ill-in administering the medication, in recognizing the signs of relapse, in bringing the patient for further treatment and in his/her rehabilitation.

Thus, families have become the mainstay of care giving for persons with mental illness. The policy of de-institutionalization has further highlighted this role of family members as the primary source of care giving for patients with mental illness. However we still look upon them only as providers of care rather than as persons who also are deeply troubled by their relatives' illness and also by the care giving process itself.

The caregiver becomes vulnerable to psychological disorders and may suffer a breakdown due to tension or overload and present with symptoms such as stress, frustration, reduced social interaction, anxiety, depression, reduced self-esteem, among others.

Caregiver Burden

The World Health Organization (WHO) states caregiver burden as the the emotional, physical, financial demands and responsibilities of an individual's illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system.^[2] Care giver burden is classified into objective and subjective burden.

Objective burden is used in reference to the physical burden of care consequent to behavioral changes of the mentally ill individual and the social effect on the caregiver's daily life, such as changes in family relations, employment and health.

Subjective burden refers to the emotional reaction of the caregivers, including perception of strain, reduced morale, anxiety and depression.^[3,4]

Importance of studying caregiver burden

By decreasing this burden on caregivers, we provide better coping to the family thereby making them better caregivers. Thus emphasizing the importance of caregivers in mental health care.

Schizophrenia

Schizophrenia has three stages in the course of illness.

1. Pre psychotic or prodromal phase

This is a period in which the subject has nonspecific symptoms that are prior to the acute phase.

2. Acute phase

This phase is defined by the presence of positive symptoms as delusions, hallucinations, disorganized speech and behavior that appear in severe form.

3. Chronic phase

This phase is characterized by the presence of negative symptoms and severe residual symptoms, and results in incapacity to create appropriate close relationships for their age, gender and familial condition and concentration and attention problems that are manifested within the social context.^[5,6]

Caregiver burden & schizophrenia

To effectively reduce caregiver burden, needs of caregivers and factors influencing caregiver burden with respect to different stages of schizophrenia are to be studied.

Multiple factors influence caregiver burden like illness related, patient related, caregiver related and social factors. As psychopathology of schizophrenia is different in different stages, which of these factors affect caregiver burden in which stage needs to be studied. This may have important implications for the clinical management of people with schizophrenia.

Current pharmacological treatment is effective only against positive symptoms but these symptoms are poorly correlated with functional outcome.^[7, 8] Negative symptoms which are not well controlled by present pharmacological management predict long-term disability better than the positive or disorganization symptoms. Negative symptoms may also be the most significant predictor of social function; in a laboratory study the severity of negative symptoms had greater predictive power than impairment of social skills on measures of work performance.

Thus, effect of psychopathology of schizophrenia on caregiver burden needs to be studied.

AIMS

1. To study the severity of caregiver burden in patients with chronic schizophrenia.
2. To study the association of severity of psychopathology with caregiver burden.
3. To study the association between various components of psychopathology like positive, negative symptoms, general psychopathology and caregiver burden.

MATERIALS AND METHODS

The Study design is clinical, instrument-rated and cross-sectional study. A total of sixty patients diagnosed as schizophrenia as per ICD-10 with duration more than two years were studied who presented with their primary caregivers between January, 2015 to April, 2015.

Ethics approval

The approval for the study was obtained from the Institution's Ethics Committee, Institute of Mental Health, Hyderabad.

Inclusion criteria

A random selection was made with inclusion criteria of patients aged more than 18 years old, diagnosis of schizophrenia as per the ICD-10 criteria, duration of illness > 2 years and on treatment for significant duration of illness.

Caregivers were more than 18 years old and caregiver were identified as 18 or above year old adult relative living with the patient, in the same environment, for at least 12 months and was involved directly in giving care to the patient and was supportive either emotionally or financially, i.e. felt most responsible for the patient.

Exclusion criteria

Patients with any documented psychiatric co-morbidity except nicotine dependence were excluded. We also did not include patients or caregivers who had any incapacitating medical illness.

Data was collected over a period of 2 months. Patients and corresponding caregivers who satisfied the criteria were interviewed after obtaining their written informed consent. The data was recorded and further aspects were studied as described below.

Tools used

Burden Assessment Schedule

The Burden Assessment Schedule (BAS) developed by Thara et al. at the Schizophrenia Research Foundation (SCARF).^[9] It is based on the principle of ‘stepwise ethnographic exploration’ described by Sell and Nagpal in 1992 while studying affected families in an effort to gauge the ‘meaning’ of giving care to a chronic psychotic person.

This is a semi-quantitative, 40-item scale measuring 9 different areas of objective and subjective caregiver burden. Each item is rated on a 3-point scale. Scores range from 40 to 120 with higher scores indicating greater burden. Internal consistency for the full scale is 0.80 as measured by the alpha coefficient. Its validity is comparable with the Family Burden Schedule (FBS) by Pai and Kapur.

2) PANSS

Positive and Negative Syndrome Scale (PANSS) is a 30-item, seven-point rating instrument that has adapted 18 items from the Brief Psychiatric Rating Scale, and 12 items from the psychopathology rating schedule.^[10] Each item on the PANSS is accompanied by a complete definition as well as detailed anchoring criteria for all seven rating points, which represent increasing levels of psychopathology from 1 indicating absence to 7 which denotes extreme symptoms.

The PANSS addresses both the presence and severity of symptoms, and the highest applicable rating point is always assigned, even if the patient meets criteria for lower ratings as well. Of the 30 psychiatric parameters assessed on the PANSS, 7 were chosen a priori to constitute a positive scale, 7 make up a negative scale, and the remaining 16 general psychopathology.

STATISTICAL ANALYSIS

The data was analysed using Microsoft excel. Continuous variables were quantified using mean and standard deviation. Categorical variables were described using percentages and Pearson product moment correlation test was used to study correlations. Statistical significance level was set at p value < 0.05. Results were displayed using scatter plot.

RESULTS

Socio demographic profile of patients: Total 60 patients and their caregivers participated in the study. Mean age (SD) of the patients was 35.78(7.18). Majority of the sample were males (63.34%), unemployed (45%), from rural background (56.4%), literate(80%), married (51.66%), belong to Hindu community (83.33%), low socio economic status (71.67%) and were from nuclear families (93.34%) as depicted in table 1. The mean age of onset of illness was 27.75 years and total mean duration of illness was 7.89 years.

Table 1: Socio-demographic profile of patients

Variable		Value
Mean Age (SD) in Years		35.78 (7.18)
Sex	Male	63.34%
	Female	36.66%
Domicile	Rural	56.4%
	Urban	43.6%
Education	Illiterate	20%
	Primary	20%
	SSC	26.67%
	Intermediate	18.33%
	Degree	15%
Occupation	Unemployed	45%
	Unskilled Worker	31.67%
	Business	13.33%
	Skilled Worker	10%
Marital Status	Unmarried	23.34%
	Married	51.66%
	S/D/W	25%
Religion	Christian	8.34%
	Hindu	83.33%
	Muslim	8.33%
Income (Per capita in RS)		8500 (6434.65)
Mean (SD)		
Socio-Economic Status	Low	71.67%
	Middle	28.33%
Family Type	Nuclear	93.34%
	Joint	6.66%
Duration of Illness in Years		7.89 (5.59)
Age of onset in years		27.75 (5.38)

Socio demographic profile of caregivers: Majority of caregivers were female (55%), parent (45%) or spouse (40%) to the patient with mean age of 43.78years. Nearly half were illiterates (43.34%) and unemployed (40%). 65% caregivers do not have any substance use history and 83.3% had no physical illness.

Mean period of association was 25 years.

Table 2: Socio-demographic profile of caregivers

Variable		Value
Mean Age (SD) in years		43.78 (12.64)
Sex	Male	45%
	Female	55%
Relation to patient	Parent	45%
	Sibling	8.34%
	Child	6.66%
	Spouse	40%
Education	Illiterate	43.34%
	Primary	33.33%
	SSC	10%
	Intermediate	5%
	Degree	8.33%
Occupation	Unemployed	40%
	Unskilled Worker	45%
	Business	11.67%
	Skilled Worker	3.33%
Habits	Nil	65%
	Alcohol	30%
	Smoking	5%
History of physical illness	Nil	83.33%
	Arthritis	8.33%
	Hypertension	8.34%
Mean period of Association (Years)		25 (10.47)

Caregiver burden and severity of psychopathology in schizophrenia

Caregiver burden score as per BAS showed a mean value of 81.75 which indicates severe burden.

Table 3: Mean scores

	Mean (SD)
BAS	81.75 (7)
PANSS	72.95 (8.14)

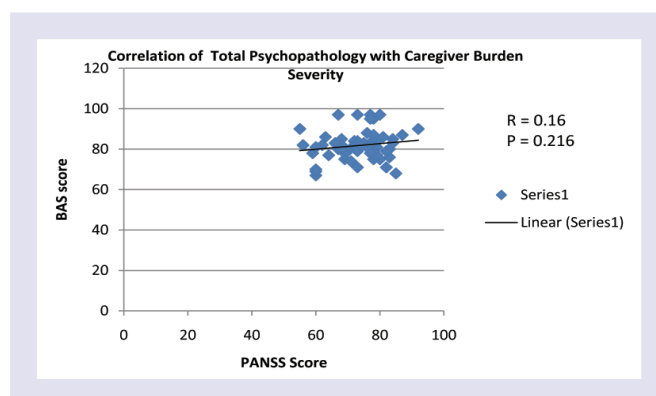
Psychopathology and Caregiver Burden

Table 4: Correlation of burden with psychopathology

Correlation of BAS Score	Coefficient (R)	P Value	Significance
PANSS Total Score	0.16	0.216	Not Significant
Positive Subscale	-0.04	0.744	Not Significant
Negative Subscale	0.39	0.0019	Significant
General Psychopathology	-0.1	<0.00001	Significant

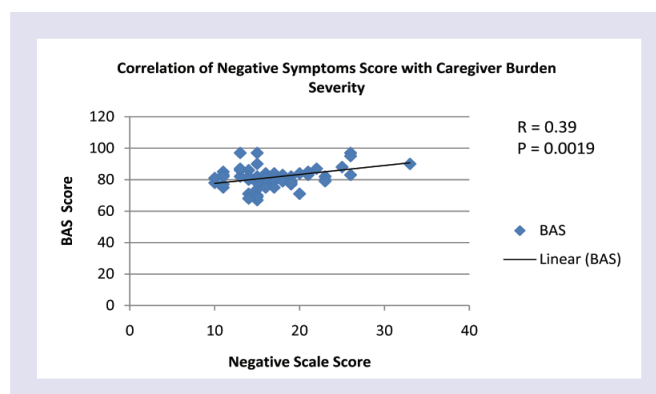
Correlation of positive symptoms, general psychopathology with caregiver burden as shown in table 4, positive symptoms and general psychopathology have negative correlation with BAS (R =0.04, 0.1 respectively) of which general psychopathology's correlation is significant (P < 0.00001).

Correlation of total severity of illness with caregiver burden there was a positive correlation between severity of total psychopathology and caregiver burden as shown in the scatter plot of figure 1 but it was not statistically significant (R = 0.16, p = 0.216).



Correlation of negative symptoms with caregiver burden

As shown in scatter plot of figure 2, a significant positive correlation was found between negative symptom score and caregiver burden (R = 0.39, p = 0.0019).



DISCUSSION

This study aimed at determining the effects of psychopathology in chronic schizophrenia patients on caregiver burden. Our results showed significant association between psycho pathology and caregiver burden.

Socio-demographic profile of patients and caregivers

In our study, female caregivers were more compared to males. In Indian culture male persons are conventionally earning members while females are caregivers. Thus, female caregivers need to be specifically targeted in intervention programs by teaching them more adaptive ways of handling stress.

When relationship with patients was considered in our study, majority were parents closely followed by spouses. Previous studies have noted that subjective burden is more in spouses compared to parents.^[11]

Unemployment and low socio economic status were major concerns emphasizing the need for social support.

Majority of caregivers were illiterates. Thus they may need to be made aware of existing facilities, government policies, disability benefits, NGO organizations and taught ways to combat stigma.

For generations, life in India revolved around the joint family system that acted as a buffer against stress. But due to rapid industrialization and urbanization, the joint family system is disintegrating and now more and more nuclear families are emerging. Caregivers in our study predominantly came from nuclear families.^[12]

Severity of caregiver burden

Caregiver burden scores in our study were high compared to previous studies.^[11] This might be because only inpatients were recruited in our study whose symptom severity would be expected to be higher compared to outpatients. The high burden scores signifies need for more attention from clinicians towards the needs of caregiver.

Severity of illness and different domains of psychopathology and their relation with caregiver burden.

Total severity of illness had positive correlation with caregiver burden in our study. This signifies severity of illness as one of the important predictors of caregiver burden along with insight, treatment adherence, coping skills, and other factors. These results were consistent with previous studies.^[13,14,15]

Association of negative symptoms with caregiver burden and its implications. Negative symptoms were positively

correlated with caregiver burden but not positive symptoms which conforms with previous literature and adds to it.^[16]

Negative symptoms were found to be associated with greater disability, poor occupational function leading to greater financial burden, are the focus of critical comments (expressed emotion) by caregivers, associated with resignation as a coping strategy in caregivers and their severity is related to greater objective burden according to previous literature.^[17-21]

Association of positive symptoms and general psychopathology with caregiver burden.

In our study, positive symptoms and general psychopathology scores had negative correlation with caregiver burden although only correlation of general psychopathology was significant.

Positive symptoms may be more significant in contributing to caregiver burden in initial stages of illness. But over the course of illness, caregivers understand the nature of symptoms and that effective services are available to manage positive symptoms.

Thus, they do not contribute to significant burden in chronic patients. Negative correlation of positive symptoms with caregiver burden found in our study could be because patients with positive symptoms can communicate, work, take better self-care than those with negative symptoms.^[22]

IMPLICATIONS

This study convincingly demonstrates that caregiver burden predictors are different in different stages of schizophrenia.

In acute stages where positive symptoms predominate, caregivers need information on emergency services and supportive counselling.

In chronic stage of schizophrenia negative symptoms predominate contributing to caregiver burden, disability and consequently more burden. In this stage, caregivers need information on rehabilitation services, supported employment, psychoeducation and financial support from government. There is also a dire need for research on medication more effective for negative symptoms.

LIMITATIONS

Our study is limited by the small sample size and it's cross sectional design. The severity of disability was not assessed which could be a confounding factor.

CONCLUSION

Caregiver burden varies with different stages of

schizophrenia. Chronic stage is characterized by predominant negative symptoms in patients and consequently greater caregiver burden. Thus, different interventions are needed for both patients and caregivers in different stages of schizophrenia to decrease caregiver burden.

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