



## **DISTRESS AND BURDEN IN THE CAREGIVERS OF MALE PATIENTS WITH PARANOID SCHIZOPHRENIA**

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### **Abstract**

**Background:** Schizophrenia is a chronic, disabling psychiatric disorder that poses numerous challenges to caregivers for its management and consequences. The disorder could give psychological distress and burden of care to the caregivers of the patients. **Methods:** To capture the distress and the burden, distress scale and burden assessment schedule were used to collect data from the caregivers of the male patients with paranoid schizophrenia. The schizophrenic patients had the symptoms such as delusions, hallucinations, disordered (confused) thinking and speech, bizarre or disorganized behavior, self-neglect, and inappropriate emotions which disturbed both the patients and their caregivers. Demographic variables such as age, religion, income, education, number of children, occupation and condom usage, were collected from the caregivers.

**Statistics:** Percentage, and mean and standard deviation were used to analyze and interpret the collected data from the sample.

Results indicated that the caregivers of paranoid schizophrenic patients had more burdens in perceived severity of the disease, burden in marital relationship and relations with others, and fewer burdens in well being and appreciation for caring.

**Conclusion:** The caregivers had more distress and perceived severity of the disease, burden in marital relationship and relations with others. The present findings could help the planners to develop strategy/ intervention to reduce distress and reduce the burden of care givers of patients with schizophrenia for better coping.

**Keywords:** Paranoid schizophrenia, distress and burden of caregivers.



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## **Introduction**

The caregivers spend more time as they live with the patients and handle the psychotic symptoms, more behavior problems and more care giving demands of the patients (Karno et al, 1987; Kopelowicz et al, 2002; Jenkins et al, 1986; Kopelowicz et al, 2003). Some other studies focused on how family attitudes and interactions could impact the patient for care giving within the family (Cook, Pickett & Cohler, 1997; Lefley, 1987; Solomon, & Draine, 1995 & 1996). Moreover family members are significantly distressed as a result of having a family member with schizophrenia. Ivarsson et al, (2004) express that family caregiver burden is complex and includes several areas such as activities in daily life, worry and social strain.

Interpersonal conflict and disruption of the daily routines can be considered as objective stressors for family caregivers (López et al, 2004; Pearlin et al, 1990). Besides, family conflict reflects the degree of burden or care giving burden to the caregivers. High levels of positive symptoms can be related to more burdensome appraised by the caregivers. Each psychiatric symptom has impact towards stigma, subjective burden and depression. For example, schizophrenia poses numerous challenges in its management and consequences to patients and family members. This illness takes a toll on the patient or ends up in hospitalization of the patient.

Indian families believe that supernatural forces are the main cause of mental illness for which they seek remedial measures from magicians for healing (Srinivasan & Thara, 2001). The caregivers have poor quality of life as they are burdened and strained for long duration (Sales, 2003) and they prefer to get very less assistance from mental health professionals (Saunders, 2003). The chronic burden of everyday living can profoundly reduce the quality of life and can decline satisfaction with the partners.

Family burden in caregivers of patients can be disability related to work and sexual problems, lack of participation in household duties and lack of self-care, satisfaction with mental health services, and social relationships, threats, nuisances, and burden due to restricted social life and leisure activities, worries about the patient's health, and their own future, and safety. Family members or caregivers could play a very important role in detecting subtle fluctuating behavior of the patients and could act therapeutically if properly prepared. It is possible to improve the environment, in which family functioning plays a major role to help for the patients.

Hence there is a distinct need to assess the extent and nature of distress and burden experienced by the caregivers of schizophrenic patients and to initiate objective measures of any intervention for the caregivers and the patients to enhance their quality of life.

**Objectives:** i). to assess psychological distress of the caregivers of male patients with paranoid schizophrenia and ii) to measure burden of the caregivers of patients with paranoid schizophrenia.

### **METHOD**

**Design:** Cross section survey design was used to measure distress and burden of care givers of the patients with paranoid schizophrenia. The patients had symptoms such as delusions, hallucinations, disordered (confused) thinking and speech, bizarre or disorganized behavior, self-neglect, and inappropriate emotions which disturbed the patients and their care givers.

**Sample:** The caregivers of male patients who came to the department of psychiatry for getting treated for paranoid schizophrenia were taken as sample for the study. Distress scale and burden assessment schedule were administered to thirty caregivers of patients. Demographic variables such as age, religion, income, education, and number of children were collected from the patients.

### **Materials:**

1. Distress Symptom Inventory (DSI): The items of distress symptom inventory, developed by Kannappan, (2006) were rated on 5-point Likert-rating scale, from “strongly disagree” to “strongly agree.” The 20 items had statements about how much people could get distress. These items were selected and modified from distress symptom inventory of Derogatis et al, (2002) in the present study. Higher scores on the inventory indicated that they had greater distress. The test- retest reliability was 0.72.

2. The Burden Assessment Schedule (BAS): It consisted of 20 items of 3-point Likert-rating scale, from “not at all” “to some extent” and very much” in which these ratings were scored 3, 2, and 1 respectively (Sell et al, 1990). The items had statements about how woman might react to various situations, activities, or behaviors. It had five sub-scales which were well being, appreciation for caring, perceived severity, marital relationship, and relations with others. Higher scores on burden schedule indicated spouses/ caregivers had greater burden of caring the patients in these situations.

**Statistical analysis:**

Mean, standard deviation and percentage were used for analyzing and interpreting the scores obtained by the scale and the schedule.

**Table 1: shows demographic variables of the caregivers of patients with paranoid schizophrenia.**

S.No	Demographic variable		Caregivers	
			N	%
1	Age	24- 30 years	9	30
		31-37 years	21	70
2	Religion	Hindu	17	56.7
		Christian	6	20.0
		Muslim	7	23.3
3	Income	Rs. >3000	7	23.3
		Rs. >5000	13	43.4
		Rs.>8000	10	33.3
4	Education	No formal education	2	6.6
		5 <sup>th</sup> standard	6	20.0
		8 <sup>th</sup> standard	11	36.7
		10 <sup>th</sup> standard	7	23.3
		> +2 level	4	13.4
5	Occupation	Weaver-	9	30.0
		Coolie	8	26.7
		Construction worker	7	23.3
		Housewife	6	20.0

The table 1 showed that majority of the patients belonged to the age group of 31-37years (70%) followed by 24-30 years (30%), and belonged to Hindu religion (56.73%) followed by Muslims (23.3%). More percentage of them had income of Rs 5000 (43.4%), education of 8<sup>th</sup> and 10<sup>th</sup> standards (36.7%) and 23.3%) respectively. Majority of the patients had the occupation of weaver (30%) followed by coolie (26.7%).

**Table 2: shows distress and burden scores of the caregivers of patients with schizophrenia**

S.No	Group	Scale	Score - Statistics				
			Level	N	Mean	S.D. %	
1		Distress care scale	Moderate	10	31.71	2.78	27.3
			severe	20	40.13	3.37	72.7
2	Givers	Burden schedule i-well being		30	48.19	2.78	80.32
				30	9.83	2.19	16.4

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ii-appreciation for caring	30	4.37	3.34	7.3
iii-perceived severity	30	14.23	2.85	23.7
iv-marital relationship	30	10.34	2.87	17.3
v- relations with others	30	9.42	2.63	15.7

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The table 2 showed the percentage of mean and standard deviation in moderate and severe level scores of distress and the burden schedule scores with sub types of their spouses. The caregivers had high mean value (40.13) in severe distress, and higher percent 72.7, followed by moderate distress (31.71) & percent 27.3. They had high mean value(48.19), in overall burden schedule score & percent 80.32 and sub-scales well being (9.83), & percent 16.4, appreciation for caring (4.37), & percent 7.3, perceived severity (14.23), & percent 23.7, marital relationship (10.34), & percent 17.3 and relations with others (9.42), & percent 15.7. These burdens of care might be due to effect of illness and could influence their social and occupational areas of functioning. The care givers had more burdens in perceived severity of disease, marital relationship, well being and less burdens in relations with others and appreciation for caring.

**Discussion:**

It would be necessary to gather more data yielded to provide a sound scientific basis. This study provides insight into the problems faced by the sufferers of the care givers and the factors determining burden. Further caregivers are challenged with financial responsibilities, missed work, disturbance of domestic routines, constraints on social and leisure activities, and reduced attention to other family members. Often family members forego work outside the home to provide care for the patients and have an unresolved grief due to the severe mental illness. Low quality of life in the patients is associated with, tobacco / alcohol abuse, having neither reliable friends nor daily contact with family.

Family intervention might be an important means of increasing the effectiveness of treatment for patients by psycho education, communication enhancement training and problem-solving skills. The scale / schedule measured the distress and burden of the caregivers of male patients who came to the department of psychiatry for getting treated for paranoid schizophrenia. Demographic variables indicated that they belonged to age of more than 24 years, and had less income, and less education. The high score in the distress indicated the greater suffering due to the patients and interference in functioning of the family. The Interference might be due influence of various factors e.g., socio- cultural factors which could influence their social

functioning. They had higher scores on burden indicating greater interference in functioning of care givers. Their mental illness could affect more in the areas of social and occupational functioning of their spouses.

### **Conclusion:**

The care givers had more symptoms of distress and more burdens in perceived severity of disease, marital relationship, well being and less burdens in relations with others and appreciation for caring. The present findings could help the planners to develop strategy/ intervention to reduce distress of the caregivers of patients with schizophrenia and reduce the family burden of their spouses for better coping.

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