



## Caregiver Burden In Families Of Patients With Schizophrenia

### KEYWORDS

caregivers burden, schizophrenia.

**M.Rajeswari**

Research Scholar, PG & Research Department of Social Work, Shrimati Indira Gandhi College, Tiruchirappalli.

**N.Sherrin Sophia**

Head, PG & Research Department of Social Work, Shrimati Indira Gandhi College, Tiruchirappalli.

### ABSTRACT

*Schizophrenia is a severe form of mental illness that affects about 7 per 1,000 of the adult population. It is estimated that globally about 29 million people have schizophrenia. The burden of caregiving is a complex multifaceted construct which may defy a uniformly agreed simple definition. Caregiver burden refers to a psychological state that ensues from the combination of physical work and emotional and social pressure involved in caring. This study aims to examine the burden of family members of patients with schizophrenia. Seventy nine family members of patients with schizophrenia who were attending Sowmanasya Hospital outpatient service in Tiruchirappalli, were assessed with Caregiver Burden Scale by Thara, Padmavati, Kumar & Srinivasan-1998. The study revealed that caregivers show a very high degree of burden. These results suggest a close monitoring of caregivers mental health and the provision of family intervention and psycho-social support.*

### Introduction

Schizophrenia is a challenging disorder that makes it difficult to distinguish between what is real and unreal, think clearly, manage emotions, relate to others, and function normally. Burden is one of the most commonly used variables in care giving research and has emerged as a critically important public health issue. With the rise of community psychiatry, one social parameter that has received some attention is the burden of care of psychiatric patients on their caregivers.

Living with a patient with schizophrenia can be nerve wrecking because of his or her behaviour, which can be unpredictable, even frightening at times. As it is difficult for most to understand the stress of the caregivers, feelings of isolation, anxiety, depression and frustration are common among caregivers who are caring for their ill relatives even when they are doing an excellent job.

The World Health Organization has estimated that about 40 - 90% of patients with schizophrenia live with their families. In developing countries, the extended family provides care for these patients in the face of poor mental health facilities. However, recent changes in family structures and rapid economic decline in such countries are threatening the support available to patients with chronic mental illness.

The impairment caused by schizophrenia limits the ability of the sufferers to remain independent in various domains of psychosocial functioning. Patients with schizophrenia, therefore, require long-term support and care which may become burdensome to their caregivers.

Family members of patients with schizophrenia have enormous roles in the care of their patients, which could negatively impact their well being. Development of interventions targeted at alleviating the burden of informal care giving is hinged on the recognition of the factors associated with the various dimensions of burden.

Caregivers are more likely to be women in many parts of the world. For example, in the United Kingdom, about 58% of the caregivers are women (Nolan, 2001). Asian studies found about 70% of family caregivers are females (Chan et al., 2009; Cheng & Chan, 2005). The World Federation of Mental Health (2010) estimated that globally, about 80% of the caregivers are women. They could be the mother, wife, or daughter of the

clients and are usually with low income. The impact of the women's intensive caregiving can be substantial. Studies showed that middle-aged and older women who provided care for an ill spouse or a spouse with disability were almost six times as likely to have depressive or anxious symptoms as were those who had no caregiving responsibilities (World Federation of Mental Health, 2010).

There is plenty of research about burden on relatives of psychotic patients; however concern for this group has increased during last decades.

Various studies have been conducted to study the burden of caregivers of schizophrenic patients. The level of burden experienced by caregivers of persons with schizophrenia is equivalent to that of caregivers of persons with other neurological (e.g., Alzheimer's disease, mental retardation) and physical (e.g., diabetes, cancer) disorders (Biegel, Sales, & Schulz, 1991; Pariente & Carpiello, 1996). Juvang, Lambert, and Lambert (2007) investigated the relationship between demographic characteristics of caregiver and family caregiver's burden when providing care for a member with schizophrenia in China. Purposive sampling technique was used to recruit 96 subjects from 3 hospitals.

The Brief Psychiatric Rating Scale, Manchester Short Assessment of Quality of Life, Groningen Social Disability Schedule and Client's Socio-demographic and Clinical History Inventory tools were used. The caregivers completed the Involvement Evaluation Questionnaire (IEQ). Subjects were grouped according to ICD-10 diagnoses: schizophrenia (n = 55), depression (n = 61), and anxiety and personality disorders (n = 25). Highly aggressive, suicidal and somatically unstable patients were excluded along with patients below 18 and over 65 years. Statistics included multiple regression analysis, ANOVA, Kruskal-Wallis and chi-square tests. The results indicated that diagnostic groups differed with respect to socio-demographics, psychopathology and quality of life, but not with respect to mean level of social functioning. Despite between-group differences, the caregiver's burden did not differ according to the diagnostic group. Of the four dimensions of burden, "worrying" and "urging" scored the highest. Majority of caregivers worried about their relative's general health (82%), future (74%) and financial status (66%). Caregivers' characteristics and not patients' explained the

largest proportion of the family burden variance (almost 23% for IEQ Tension). Higher burden seemed to be associated with the carer's age, being a parent and number of hours spent weekly on caring for the ill relative. Lower burden was associated with the carers' subjective feelings of being able to cope with problems and to pursue their own activities. Longer history of patient's illness led to higher IEQ Tension. Wong, (2008) examined the extent of burden reported by families of patients during a putative prodromal period and in the after-math of psychosis onset. 23 family members of patients with emerging or early psychosis participated in the exploratory study, using the Family Experiences Interview Schedule to assess both.

**OBJECTIVES**

- To assess the caregiver burden of the respondents.
- To give suitable suggestions to reduce the level of burden among the respondents.

**METHOD AND PARTICIPANTS**

The participants were the caregivers who were taking care of the schizophrenic patients (Male-54, Female-25, N-79) at Sowmanasya Hospital, Trichirappalli. Purposive sampling was adopted for the present study and it is descriptive in nature.

**TOOLS OF DATA COLLECTION**

Caregiver burden scale by Thara, Padmavati, Kumar & Srinivasan-(1998) was adopted to collect the data.

**Analysis**

**Table 1 - Socio demographic details of the respondents**

S.No.	Particulars	No. Respondents	Percentage
1.	<b>Age</b>		
	Below 25	5	6.3
	26-30	14	17.7
	31-35	7	8.9
	36-40	17	21.5
2.	Above40	36	45.6
	<b>Gender</b>		
3.	Female	54	68.4
	Male	25	31.6
4.	<b>Educational status</b>		
	Primary	33	41.8
	Secondary	27	34.2
	Undergraduate	2	2.5
	Post Graduate	5	6.3
	Diploma	1	1.3
	Illiterate	11	13.9
5.	<b>Marital Status</b>		
	Unmarried	15	18.9
6.	Married	63	79.7
	<b>Occupation</b>		
	Coolie	22	27.8
	Private	9	11.3
	Government	16	20.2
7.	Unemployed	9	11.3
	<b>Income</b>		
	Rs1000-3000	30	37.9
	Rs3001-5000	12	15.1
	Rs5001-8000	12	15.1
8.	AboveRs8000	16	20.2
	No Income	39	49.3
	<b>Native Background</b>		
9.	Rural	40	50.6
	Urban		

The above Table (No.1) shows the age of the respondents. It was observed that 46 percent of the respondents were above 40 years of age, 21.5 percent of the respondents belong to the age group of 35-40 years, 17.7 percent of the respondents were in the age group of 26- 30 years, 8.9 percent were in the age group of 31-35 years and least (6.3%) were 25 years of age. Majority (68.4%) of the respondents were female and 31.6 per cent were males.

Regarding the educational status of the respondents it was observed that 41.8 per cent had primary level of education, 34.2 per cent secondary, 13.9 per cent were illiterates, 6.3 were post graduates. 2.5 per cent were undergraduates and very meagre respondents (1.3%) were diploma holders. This indicates that educational backgrounds of the respondents were found to be poor, which might be the major cause of burden among the respondents.

Majority(79.7 %) of the respondents were married and 18.9 percent were unmarried.

While analyzing the occupational status of the respondents 40.5 per cent were coolies, 27.8 private, 20.2 per cent were unemployed, 11.3 per cent were government employees.

The income of the respondents shows that 37.9 per cent of the respondents income were Rs 3001-5000, 20.2 per cent had no income due to unemployment, 15.1 per cent were Rs 5001-8000, same (15.1%) of the respondents income were above Rs 5000 and least(11.3%) Rs 1000 - 3000. Occupation and income have great impact on the quality of life and also increase the level burden among the caregivers.

**Table 2 Distribution of respondents based on their knowledge of mental illness**

S.No	Knowledge of Mental Illness	No. of respondents	Percentage
1	Yes		
2	No	59	74.7
		20	25.3
	<b>Total</b>	79	100

It was interesting to observe that 74.7 percent of the respondents had knowledge about Mental illness and remaining (25 percent) had no knowledge about mental illness. In addition, studies have shown family psychoeducation interventions reduces patient symptoms, as well as inpatient treatment utilization; however, through the above findings it is not known whether or not these interventions reduce family burden.

**Table 3 Distribution of respondents relationship to the patient**

S.No	Relationship to the patient	No. of respondents	Percentage
1	Parent	43	54.4
2	Spouse/partner	10	12.6
3	Sibling	9	11.3
4	Children	14	17.7
5	Relative	3	3.7
	<b>Total</b>	79	100

The above table indicates that more than half (54%) were parents to the patient, 17.7 per cent were children, who were taking care of the the patient at the time of study, 12.6

percent were spouse or partner, 11.3 were siblings and few (3.7%) were relatives to the patients.

**Table 4**  
Distribution of respondents by their level of burden

S. No	Level of Burden	No. of Respondents	Percentage
1	Low	39	49.4
2	High	40	50.6
	Total	79	100

The above table shows that half of the respondents (51%) had high level of burden and remaining (49 percent) of the respondent's burden was found to be low. More generally, this study demonstrates that it may be caregivers' awareness of patient difficulties (e.g., suicidal ideation, substance use, positive, and negative symptoms) rather than the actual presence of these difficulties that is associated with increased burden. The adage "what you don't know can't hurt you" appears to apply to family participants in this investigation.

**Table 5**  
Difference between Gender of the respondents and level of burden

S.No	Gender	N	Mean	Standard Deviation	Statistical Inference
1.	Female	54	75.7600	10.13772	df= 77 p<-.620 significant
2.	Male	25	74.1111	11.36142	

The above table indicates that there is a significant difference between gender of the respondents and burden. These mean scores indicate that level of burden is higher among female respondents than male.

**Table 6**  
Difference between native background of the respondents and level of burden

S.No	Native Background	N	Mean	Std. Deviation	Statistical Inference
1.	Rural	39	75.4872	10.05739	t=.497 df=77 P<0.05 Not Significant
2.	Urban	40	73.8000	11.82609	

The above table indicates that there is no significant difference between the native background of the respondents and level of burden.

**Table 7**  
Oneway ANOVA difference between age of the respondents and level of burden

Age	Mean	SD	SS	Df	MS	Statistical Inference
Between groups	77.2000	11.36662	1580.520	4	395.130	F= 3.761 P=0.08 p> 0.05 Significant
<25 (n=5)						
26-30 (n=14)	71.0000	8.54850				
31-35 (n=7)	68.5714	11.75949				
36-40 (n=17)	69.8824	10.70562				
> 40 (n=36)	79.1111	10.20302				
Within groups			7773.835	74	105.052	

The above table indicates that a significant difference between the age of the respondents and level of burden.

**Table 8**  
Oneway ANOVA difference between educational qualification of the respondents and level of burden

Educational qualification	Mean	S. D	SS	Df	MS	Statistical Inference
Between Groups	78.8485	78.8485	9.34118	5	473.387	F= 4.946.001 P<000
Primary(n=33)						
Higher Secondary(n=27)	72.5185	72.5185	11.13681			Significant
Under Graduate(n=2)	70.0000	70.0000	1.41421			
Post Graduate (n=5)	58.2000	58.2000	8.67179			
Diploma(n=1)	60.0000	60.0000	8.17090			
Illiterate(n=11)	76.8182	76.8182	10.95115			
Within Groups				73	95.718	

The above table shows that there is a significant difference between educational qualification of the respondents and level of burden.

**SUGGESTIONS**

Psycho education should be provided for teaching patients and families about mental disorders, their treatments, personal coping techniques, and resources. This form of intervention would help people to be better participants in their own care if knowledge deficits are removed. By teaching skills such as problem solving and communication, it would increase carers' coping ability with their situation.

The availability of a counseling service for the caregivers to help them resolve problems and overcome their difficulties will put them in a better position to carry out the caregiving duties effectively.

Having looked at the findings which pointed to burden in all the caregivers with some groups being more affected it is then crucial to ensure that these caregivers receive adequate support in terms of services. The following domains should be established to have implications for service delivery

- > Mobilizing of informal support
- > Provision of formal support
- > Information and education
- > Financial assistance
- > Employment assistance

- Promotion of community based services
- Education and Training
- Community education

This would reduce the burden and improve their quality of life. Once burn out, caregiving is no longer a healthy option for either the person they are caring for. So it's important to watch for the warning signs of caregiver burnout and take action right away when they recognize the problem.

When familial networks and support from friends, neighbours and colleagues are not available, the caregivers could benefit from self help family support groups and voluntary organizations which mental health professionals can draw help for the isolated caregivers.

## CONCLUSION

Recommendations commonly made in these studies are to meet the needs of these families to ease their burden, and family orientation interventions need to be developed. Many authors highlighted that professional support could, apart from meeting needs of the families and easing their burden, help the families become more effective carers at home. Such an idea should become a core value for making policies of mental health care today.

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