

## The Level of Perceived Family Burden Among the Primary Caregivers of Chronic Schizophrenia Patients in A Tertiary Care Hospital, Erode.

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### Abstract:

#### Background:

It can be a difficult task to provide care to the patients living with mental health issues, especially with chronic diseases such as schizophrenia where the patient loses touch with reality.

#### Aim:

The aim of the research was to assess the level of perceived family burden, among the primary caregivers of chronic schizophrenia patients and socio-demographic correlates of caregiver's burden in schizophrenia. The study also evaluated the factors affecting the caregiver's burden.

#### Materials and Methods:

A descriptive research design was used for the study. The study population consisted of 100 primary caregivers of chronic schizophrenia patients who were attending the outpatient department of Government Erode Medical College Perundurai, Erode. A purposive sampling technique was used to select the samples. In order to collect the data, the tool

comprised of socio-demographic variables, Burden Assessment Schedule of SCARF (BASS,1995) to assess the level of perceived family burden.

### **Results:**

Mean age of patients was 29.7 SD (8.6) years. Of the 368 caregivers, 81.5% were parents, mean age was 58.1 years (SD 19.6). The result revealed that among the primary caregivers 48% are having mild burden, 36% of them are having moderate burden and 16% of them having severe burden. The association between the level of perceived family burden and demographic variables shows that age ( $\chi^2=8.97$ ), duration of illness ( $\chi^2=7.69$ ), and relationship with the patients ( $\chi^2=7.44$ ) are significantly associated with their level of burden. More aged, less income, duration of illness and wife group are having more burden than others.

### **Conclusion:**

Caregivers of schizophrenia patients experience enormous burden and are potential “high risk group” for mental disorders. The caregivers should receive an adequate support for maintaining their own mental health. they should be provided support for maintaining their mental health. Particularly, vulnerable are females, elderly, low-income groups, and longer duration of care. They should be provided with adequate support.

**Keywords:** Burden, caregivers, mental health, schizophrenia

### **Introduction:**

Since mental wellness is typically seen as a good quality, even those without diagnosable mental health conditions can achieve higher levels of mental health. The ability to live a full and creative life and the adaptability to deal with life's unavoidable challenges are highlighted by mental health [1]. The existence of burden suggests a rift in a person's mental health as well as subjective well-being [2].

Schizophrenia is a severe mental disease that has devastating effects on both the patient and the patient's family. This is because the disease is chronic and frequently results in long-term disability. Both positive symptoms like aggressive behaviour, delusions, and hallucinations as well as negative symptoms like lack of motivation and insufficient self-care cause issues for patients. The ability to form social connections is frequently weakened, and job possibilities are constrained. Many patients have recovered or made substantial improvements thanks to modern treatment techniques, but many still exhibit deficits in a number of functional areas. As a result, people with chronic mental illness, their families, and the society all bear a heavy burden. [3-5]

Schizophrenia creeps up on a person gradually, so it takes a while before anyone notices anything is amiss. It can occasionally manifest suddenly, with significant behavioural changes happening over a period of a few weeks or even a few days [6].

The family has long been acknowledged as playing a significant role in the development and prognosis of mental disease. Early research on schizophrenia concentrated on the family's potential etiological role; however, current thinking includes the family as a "reactor" to a member's mental illness. This has sparked interest in the various issues that

families experience as a result of the patient's illness, such as monetary challenges or disruptions to daily routines. Social or family stress refers to the totality of these challenges. Age, gender, job position, length and severity of the illness, as well as carer characteristics, all have an impact on the burden.

A continuous stressor may be considered to be providing care for a family member who has schizophrenia. This is a result of the illness's ongoing nature, the long-term disability, and the loss of control over the circumstance. In order to cope with the demands of such a stressful situation, carers use psychological processes like coping practises.

One of the effects of the deinstitutionalization movement in the west has been the involvement of the family as the main locus of care for a mentally ill relative. However, in the Indian culture, families have frequently taken on the responsibility of caring for their psychologically ill loved ones. This is a result of both the current, insufficient mental health infrastructure and the societal and cultural contexts. In India, families are engaged in the majority of the care provided to people with severe mental illness. They are acknowledged as playing a significant role in choices about participation or disengagement in the therapeutic process, medication supervision, day-to-day care, and emotional support for the person [7].

The role of health professionals in acknowledging the burden of carers is crucial, particularly for mental health doctors. They are in a position to provide assistance and recommend clients to community organisations, social workers, and mental health nurses for additional assistance. Such a step would guarantee the welfare of families who are caring for mentally ill patients. To do that, the mental health nurse must evaluate the stress and coping mechanisms of caretakers.

Following a thorough study of the literature in this field, it was discovered that few Indian researchers have conducted any formal scientific research on the degree of perceived family burden. Therefore, it was thought that a scientific study was necessary to look into those variables.

1. To assess the level of perceived family burden among the primary caregivers of chronic schizophrenia patients
2. To find out the association between the perceived family burden and selected demographic variables

A descriptive study to assess the level of perceived family burden among the primary caregivers of chronic schizophrenia patients in a tertiary care hospital at Erode, Tamilnadu.

### **Methodology:**

**Research approach:** In this study, the researcher used a quantitative approach.

**Research design:** The research design used for this study is a descriptive design.

***Setting of the study:***

The Government Erode Medical College Hospital in Perundurai, Erode, was the site of the research. It offers services like short- and long-term care facilities located in institutions as well as community-based initiatives to help people with mental disabilities improve the quality of their lives. Every day, about 20 to 30 patients receive outpatient treatment. The participants in this research were the main carers of chronic schizophrenia patients who were seeking treatment at the Government Erode Medical College Hospital in Perundurai, Tamil Nadu, and visiting the outpatient department.

***Sampling technique:***

The purposive sampling technique was used to select the sample based on the inclusion criteria.

***Sample size:***

A sample of 100 primary caregivers of chronic schizophrenia patients who were receiving treatment and attending outpatient department of Government Erode Medical College Hospital, Perundurai, Tamilnadu.

***Inclusion Criteria: -***

The primary care givers who

- were parent, spouse, sister/brother, children of the index patient.
- were adults above the age of 20 years.
- were available during the study.
- could understand and speak Tamil or English.
- were actively involved in the care of the patients at least 1 year prior to the interview.

***Exclusion Criteria: -***

The primary caregivers who

- were below the age of 20 years.
- were not willing to participate in the study.
- could not understand and speak Tamil or English.

***Research tool and technique:***

***Description of the tool:*** The tool consisted of section I and section II.

***Section I:*** It dealt with the socio demographic data of caregivers such as sex, age, education, marital status, occupation, income, relationship to patient and the duration of care.

***Section II: Burden Assessment schedule of SCARF (BASS 1995):***

This is a 40-item scale, which taps both the subjective and objective components of burden. The scale was developed using the stepwise ethnographic method on caregivers of

schizophrenic patients attending the outpatient department at the Government General Hospital, Chennai and at the Schizophrenia Research Foundation (SCARF). The domains of burden assessed by the tool are:

1. Emotional burden
2. Caregiver health
3. Family relations
4. Caregiver occupation
5. Finance
6. Patient behaviour
7. Social relations

The items are rated on a 3-point scale, with 'not at all' marked as 1 and 'very much' marked as 3. Some of the items are reverse coded, depending on the way the questions are framed. Scores range from 40-120, with higher scores indicating higher burden.

***Data collection procedure:***

The data collection period was for 6 weeks. Subjects were selected by purposive sampling technique. The researcher collected data from the primary care givers of chronic schizophrenia patients who fulfil the inclusion criteria. The purpose of this study was explained to each one of them to obtain verbal consent. Each subject was interviewed separately for 30-40 minutes.

**Results:**

**Frequency and percentage distribution of demographic variables of primary caregivers of chronic schizophrenia patients.**

S.No	Demographic variables		Number	Percentage
1.	Age	20-30 yrs	23	23.0%
		30- 40 yrs	25	25.0%
		40-50 yrs	16	16.0%
		50-60 yrs	23	23.0%
		60-70 yrs	13	13.0%
2.	Gender	Male	60	60.0%
		Female	40	40.0%
3.	Domicile	Rural	64	64.0%
		Urban	36	36.0%
4.	Education status	Illiterate	11	11.0%
		Primary	5	5.0%
		Secondary	19	19.0%
		High secondary	28	28.0%
		Graduate	30	30.0%
		Post Graduate	7	7.0%
5.	Marital status	Married	88	88.0%
		Unmarried	12	12.0%
6.	Type of family	Joint family	42	42.0%
		Nuclear family	58	58.0%
7.	Family size	<5	58	58.0%

		5-8	37	37.0%
		>8	5	5.0%
8.	Occupation	Unemployed	8	8.0%
		Professional	39	39.0%
		Retired	10	10.0%
		Housewife	20	20.0%
		Unskilled worker	9	9.0%
		Business	14	14.0%
9.	Monthly income	<Rs.2000	18	18.0%
		Rs.2001-5000	44	44.0%
		Rs.5001-10000	14	14.0%
		>Rs.10000	24	24.0%
10.	Religion	Hindu	84	84.0%
		Muslim	6	6.0%
		Christian	10	10.0%
11.	Mother Tongue	Tamil	98	98.0%
		Other	2	2.0%
12.	Relationship with patient	Mother	20	20.0%
		Father	11	11.0%
		Brother	8	8.0%
		Sister	11	11.0%
		Husband	27	27.0%
		Wife	11	11.0%
		Daughter	2	2.0%
		Son	10	10.0%
13.	Duration of stay with patient	>10 yrs	53	53.0%
		7-9 yrs	9	9.0%
		4-6 yrs	12	12.0%
		1-3 yrs	26	26.0%
14.	Health status of care giver	Healthy	91	91.0%
		Unhealthy	9	9.0%
15.	Helping people	Family members	98	98.0%
		Neighbours	1	1.0%
		Religious persons	1	1.0%

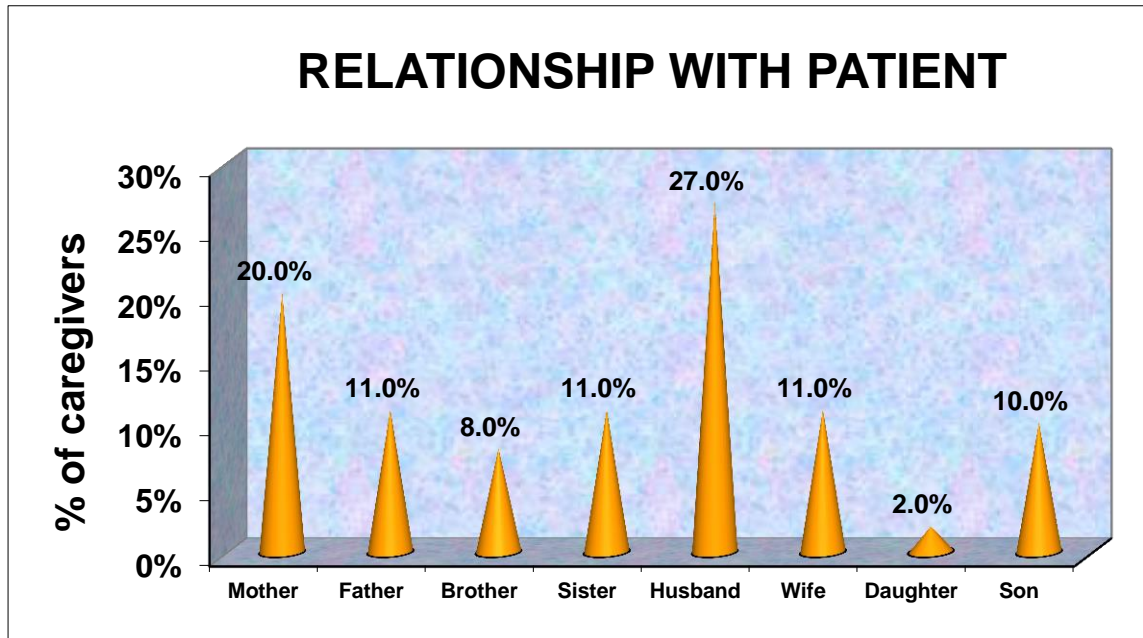
**Table No.1 shows the demographic information of primary caregivers those who are participated in the study.**

Table 1's statistics revealed that 25% of primary carers were in their 30s or 40s, 23% were in their 20s or 30s, 23% were in their 50s or 60s, 16% were in their 40s or 50s, and 13% were in their 60s or 70s. 60% of main carers were male and 40% were female, according to gender. 36% of the main carers were from cities, compared to 64% who were from rural areas. In terms of schooling, 11% of primary carers were illiterate, 30% were graduates, 28% had upper secondary education, 19% were in the secondary level, and 5% were in the primary level. 88% of the main carers were married, and 12% were single, in terms of marital status.

In terms of family structure, 58% were nuclear families and 42% belonged to joint families. 58% of families had fewer than five people, 37% had six to eight members, and 5% had more than eight. Regarding the main carers' occupations, 39% were professionals, 20% were housewives, 14% were business owners, 10% were retirees, 9% were unskilled workers,

and 8% were unemployed. Considering Monthly Income, 44% made between Rs. 2001 and Rs. 5000 per month, while 24% made over Rs. 14% of main carers made between Rs. 5001 and 10,000, and 18% made less than Rs. 2000.

**FIGURE 1: DISTRIBUTION OF SAMPLES IN TERMS OF RELATIONSHIP WITH PATIENT**



- Level of perceived family burden among the primary caregivers of chronic schizophrenia patients.

**Table No.2 : LEVEL OF PERCEIVED FAMILY BURDEN**

S.No	Level of burden	No. of caregivers	Percentage
1.	Mild	48	48.0%
2.	Moderate	36	36.0%
3.	Severe	16	16.0%
	<b>Total</b>	<b>100</b>	<b>100%</b>

Table 2 showed that the primary caregivers 48% are having mild burden, 36% of them having moderate burden and 16% of them having severe burden.

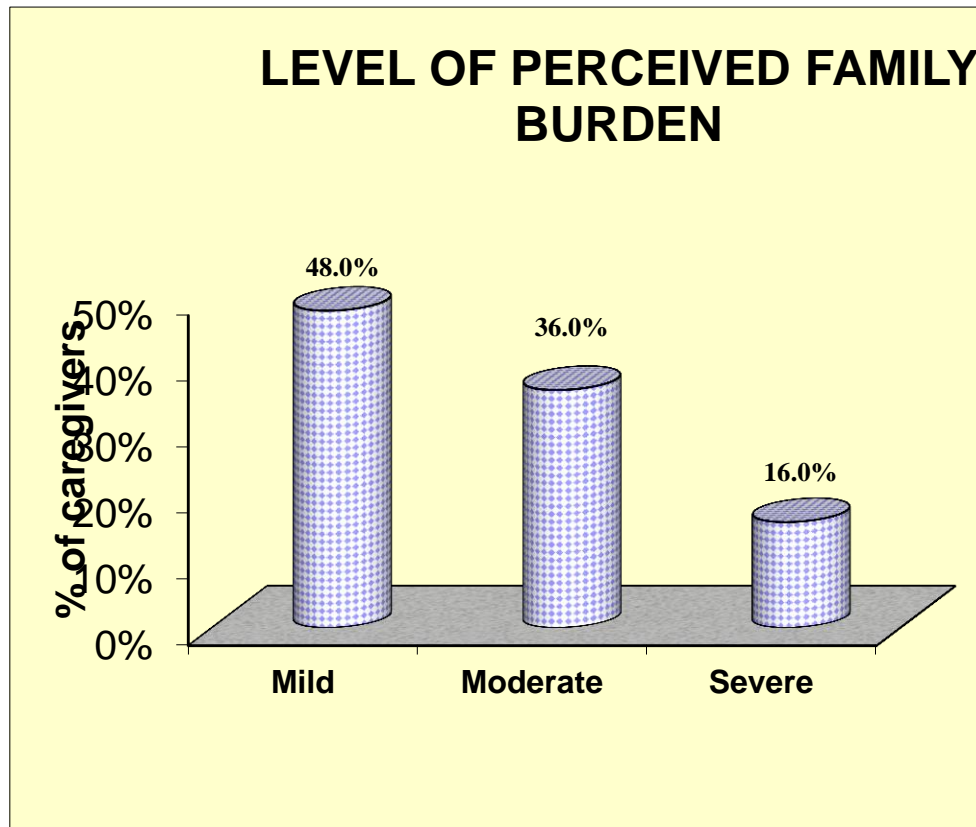
**Table No.3 : OVERALL PERCEIVED FAMILY BURDEN SCORE**

	No. of questions	Min-Max score	Mean $\pm$ SD	Percentage of burden
Burden score	40	40-120	82.87 $\pm$ 14.28	69.1%

Table 3 shows the overall perceived family burden among the primary caregivers of chronic schizophrenia patients.

They are scored 82.87 out of 120 score, so on an average 69% they are having perceived family burden.

**FIGURE 2: DISTRIBUTION OF SAMPLES IN TERMS OF LEVEL OF PERCEIVED FAMILY BURDEN**



**Table 4: ASSOCIATION BETWEEN LEVEL OF BURDEN AND DEMOGRAPHIC VARIABLES**

Demographic variables		Level of burden						Total	Chisquare test
		Mild		Moderate		Severe			
		n	%	n	%	n	%		
Age	<=50 yrs	33	51.6%	24	37.5%	7	10.9%	64	$\chi^2=8.97$
	>50 yrs	15	41.7%	12	33.3%	9	25.0%	36	
Education	Illiterate/Primary	4	25.0%	8	50.0%	4	25.0%	16	$\chi^2=4.10$
	Others	44	52.4%	28	33.3%	12	14.3%	84	
income	<= Rs.5000	25	40.3%	24	38.7%	13	21.0%	62	$\chi^2=5.98$



	>Rs.5000	23	60.5%	12	31.6%	3	7.9%	38	
Duration	>10 yrs	20	37.7%	20	37.7%	13	24.5%	53	$\chi^2=7.69$
	$\leq 10$ yrs	28	59.6%	16	34.0%	3	6.4%	47	
Relationship with patient	Mother/father/sister/brother	30	60.0%	16	32.0%	4	8.0%	50	$\chi^2=7.44$
	Wife/husband/daughter/son	18	36.0%	20	40.0%	12	24.0%	50	
Family size	< 5	29	50.0%	19	32.8%	10	17.2%	58	$\chi^2=0.65$
	$\geq 5$	19	45.2%	17	40.5%	6	14.3%	42	
Occupation	Housewife/unemployed/retired	16	42.1%	15	39.5%	7	18.4%	38	$\chi^2=0.87$
	Others	32	51.6%	21	33.9%	9	14.5%	62	
Gender	Male	30	50.0%	24	40.0%	6	10.0%	60	$\chi^2=4.16$
	Female	18	45.0%	12	30.0%	10	25.0%	40	
Marital status	Married	40	45.5%	32	36.4%	16	18.2%	88	$\chi^2=3.19$
	Unmarried	8	66.7%	4	33.3%			12	
Type of Family	Joint family	20	47.6%	17	40.5%	5	11.9%	42	$\chi^2=1.16$
	Nuclear family	28	48.3%	19	32.8%	11	19.0%	58	
Health status	Healthy	46	50.5%	32	35.2%	13	14.3%	91	$\chi^2=3.42$
	Un healthy	2	22.2%	4	44.4%	3	33.3%	9	

Table no. 4: shows the association between demographic variables and caregivers' level of burden. Age, duration of illness and relationship with patients are significantly associated with their level of burden. More aged, less income, long time illness and wife groups are having more burden.

**Discussion:****To assess the level of perceived family burden among the primary caregivers of chronic schizophrenia patients.**

A statistical analysis of the level of perceived family burden (Table 2&3) showed that 16 patients (16%) and a maximum of 48 main carers (48%) each experienced mild, moderate, and severe burdens, respectively. Numerous studies conducted in the west [8] have documented the effect of illness on the physical and mental health of the carers as well as the disruption of social relationships, especially feelings of social isolation. Identical results have been reported in an Indian context by [9]. As a consequence, the outcomes are in line with these conclusions.

With these results, the researcher came to the conclusion that having adequate income, family support, and knowledge of the disease condition help carers adopt a mild level of family burden, whereas those with less knowledge, inadequate income, and dysfunctional family relationships lead carers to adopt a moderate and severe level of family burden.

**To find out the association between the perceived family burden and selected demographic variables (such as age, gender, religion, marital status, education, occupation, income, relationship with the patient and duration of illness).**

Table No. 4 demonstrated that among socio-demographic factors, age, illness duration, and connection with patients are significantly related with their level of burden. More burdensome factors include increased age, declining income, chronic disease, and wife groups.

This finding was supported by [11] who performed a study on "the perception of burden by carers of patients with schizophrenia" supported this conclusion. At the Institute of Mental Health and Hospital, Agra, the OPD performed interviews with 34 carers of schizophrenia patients using the Thara et al. Burden Assessment Schedule (BAS) [12]. Generally speaking, caretakers of middle-aged patients reported feeling less of a burden. Urban residence and patient support, residence in Agra and the influence of other family members, and residence in Agra and the routine of the carer all showed a weakly positive association.

The caregiver's bodily and emotional health, as well as accepting responsibility, had a weak positive correlation with age of less than 30 years. The correlation between urban residence and patient support, residence in Agra and impact on other relationships, residence in Agra and impact on carer routine, residence in Agra and impact on carers' physical and mental health, and correlation between age less than 30 years and adult children with mental illness had higher rates of chronic health conditions were all significant up to 5% probability level ( $p < 0.05$ ) in the t test for population correlation.

The primary carers of mentally ill outpatients recruited from eight hospitals in Montreal, Canada, were the subjects of a research by Richard et al. [13] to characterise subjective burden and to determine the predictors of burden in primary carers. Only 12% of the main carers said they had no subjective burden in addressing one or more patient-

presented challenges. High levels of carer burden were caused by behaviours related to the patients' depressive state or affect, symptom-related patient behaviours, and poor social interaction. Regardless of their age, profession, or relationship to the patient, women who were the main carers reported feeling a larger subjective burden.

Lower age is linked to more responsibility. Who will take care of the patients after they pass away is one of the worries of caretakers of chronic psychotic patients, particularly parents, and this worry may be to blame for older patients carrying a heavier load. [14-15]

Greater weight has been linked to illnesses that last longer. However, the length of the sickness may need to be compared to the severity of the psychopathology; the better the patient's functioning, the lighter the load. Greater overall burden and burden resulting from the patient's conduct and social interactions are both associated with psychopathology severity [15]. According to studies, carer anxiety increases as symptoms become more severe. The negative symptoms of slowness, inactivity, and self-care [16] as well as aggressive, delusional, and hallucinatory symptoms caused caretakers a great deal of distress. The findings of this part imply that although the patients' mental health is stable, subjective burden—including social exclusion, stigma, and problems in the community—is still felt even though objective burden is not. This is in line with research showing a substantial and favourable correlation between objective burden and family distress, social isolation, and community problems [17].

With these results, the researcher came to the conclusion that a person's level of burden is greatly influenced by their age, the length of their illness, and their relationships with the patients. Age, income, length of illness, and spouses' burdens are all higher than average. This is due to the fact that elderly people worry about having to care for their patients after they pass away, and this worry combined with reduced income causes the person to experience more burden.

### **Recommendations: -**

- ♣ A similar study can be conducted with large sample for generalization.
- ♣ A comparative study can be done at rural and urban areas.
- ♣ A comparative study can be done among caregivers of chronic schizophrenia and other psychiatric illnesses.
- ♣ A comparative study can be done among caregivers of chronic schizophrenia patients in different hospitals.

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**IEC Approval:**

Institutional Ethics Committee Approval from GOVERNMENT ERODE MEDICAL COLLEGE & HOSPITAL PERUNDURAI obtained with vide reference IEC/001-5/GEMC&H/2020 on 31.07.2020.

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**Declaration of interests:**

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