



# A STUDY TO ASSESS THE LEVEL OF FAMILY BURDEN AMONG CARE PROVIDERS OF CLIENTS WITH SCHIZOPHRENIA AT A SELECTED SETTING IN COIMBATORE, TAMILNADU

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## ABSTRACT

### Statement of the Problem

A study to assess the level of family burden among care providers of clients with schizophrenia at a selected setting in Coimbatore, Tamilnadu.

### Objectives

1. To assess the level of family burden among the care providers of client with schizophrenia.
2. To associate the level of family burden with the selected demographic variables of the care providers of client with schizophrenia.

### Methods & Materials

A non-experimental descriptive research design was used in the study. The study was conducted at Kongunadu Mananala Arakkattalai, Coimbatore. After a formal permission and consent from the samples, data was collected. A non-probability purposive sampling technique was used to select the sample size, which was noted to be 100. The tools consisted of two sections: Section A - Demographical Variables and Section B – Standardized Questionnaire.

### Results

The findings revealed that care givers suffer from 24(24%) of the respondents low, 48(48%) of the respondents moderate, 28(28%) of the respondents high level of family burden. The findings also indicated that there was no statistically significant association found between the level of family burden care providers with the demographic variables.

### Conclusion

The study concluded that care providers suffer from moderate level of family burden. So, need to provide psychological assistance to the caregivers to help them cope with the burden, stress and anxiety.

**KEY WORDS:** Assess, Family burden, Caregiver, Schizophrenia, Clients.

## INTRODUCTION

Schizophrenia is the most common of all psychiatric disorders and is prevalent in all cultures across the world. About 15 % of new admission in mental hospitals is schizophrenic patients. It has been estimated that patients diagnosed as having schizophrenia occupy 50% of all mental hospital beds. About three-four a thousand in each community suffer from dementia praecox. About 1% of the general population stands the risk of developing this disease in their lifetime. Schizophrenia has a global prevalence of 0.3-0.7%. In India, the prevalence rate of schizophrenia is high. The epidemiological study concludes that prevalence rate was 2.62 cases per 1000 population.

It is one of the major mental disorders characterized by abnormalities in perception or expression of reality. The onset of symptoms usually happens in young adulthood. Even with available treatments, most people with Schizophrenia continue to experience symptoms throughout their lives. This will create a profound burden in the lives of their family members. Families touched by mental illness are often faced with significant financial burdens that arise from healthcare costs and job loss. A study done in India showed that the antipsychotics are affordable to the family,

but the treatment expenditure of co-morbidity, side effects and cost of consultation including travel add to the burden for the family.

Caregiver burden has been defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member (Stucki & Mulvey, 2000).

The number of people with schizophrenia in the world, particularly in developing countries, is increasing and 1 out of 100 people (approx) in the world suffer from schizophrenia (Mental Health Research Association, 2006).

According to World Health Organization (WHO) report 2001, bipolar affective disorder and schizophrenia find a place in the list of most disabling illness for the most productive age group of 15-44 years. Until 1950s, a large number of these patients used to be confined to the walls of the mental hospitals. With the advances in the psychopharmacology and growing emphasis on outpatient treatment in psychiatry, most patients with these disorders are being looked after by their families thus deinstitutionalization became possible.

It is a multidimensional response to physical, psychological, emotional, social, and financial stressors



associated with the care-giving experience. The burden can be objective or subjective. Objective burden is defined as readily verifiable behavioral phenomena. Example: Negative patient symptoms; caregiver's life disrupted in terms of domestic routine, social activities, and leisure; social isolation; problems related to finance and employment; effects on the health of the entire family; and the unusual behavior of the patient. Subjective burden comprises emotional stressors such as fear, sadness, anger, guilt, loss, stigma, rejection, etc., on the caregiver.

The shift towards community care for patients with mental disease has resulted in the transfer of responsibility of their day-to-day care to their family members, which has led to profound psychosocial, physical, and financial burden on the patients' families.

Schizophrenia is found in all societies and geographical areas and is a major cause of death in patients. About 15% of new admissions in mental hospitals are schizophrenia cases, and it has been estimated that they occupy 50% of the hospital beds. About 3-4% per 1000 people in every community suffer from schizophrenia.

About of the general population carries the risk of developing this disease in their lifetime. India ranks among the highest in the prevalence rate of schizophrenia. Amongst the epidemiological studies in India, the study of functional psychosis in urban community (SOFPU) in Madras is the most confounding one. It was a multistage census survey wherein the prevalence rate of schizophrenia was estimated to be at 2.62/1000 people.

The World Federation of Mental Health estimates that 80% of the caregivers in the world are female. They could be the spouse, mother, or daughter of the patient. Studies have shown that women, who have to care for a mentally ill patient, are prone to have six times more depressive and anxiety symptoms than those who have no such liability. It has been reported that factors influencing the caregiver burden include the gender and age of the patient, severity of the disease, cultural factors, stigma, duration of the disease, and disability. Studies exploring the relationship between the economic condition and caregiver burden have shown that a lower socioeconomic level is associated with increased caregiver burden.

The World Federation of Mental Health has assessed the burden of those providing care to patients with chronic diseases as a global problem and has announced that caring for these patients requires continuous energy, knowledge, empathy, and economic power, and that it influences the daily living of the caregivers to a large extent. While attempting to establish a balance between their jobs, families, and patient care, caregivers usually neglect their own physical and mental health.

The negative impacts of persons with a serious mental illness on their family members have been explored since the 1950s, and the term "caregiver burden" began to be used in the 1970s. It is a widely accepted concept and includes all of the physical, mental, social, and economic problems experienced by the relatives of an individual with a chronic mental illness. Some studies have demonstrated that caregivers usually do not have the knowledge and competency necessary for providing the appropriate care to such patients.

The burden on the family caregivers results in negative consequences not only for themselves but also for the patients, other family members, and the health care system as a whole. It affects their physical, emotional, and economic status.

Emotional distress affects the ability to cope with stress as well as productivity and thus the impact of the mental illness is enormous. Other negative implications among the family members include alcohol and substance abuse, delinquent behavior and impaired quality of life. Interest is growing in the field of mental health around the families who care for their mentally ill members. The interest generated has been due to factors such as deinstitutionalization of the mentally ill, increasing professional recognition of the family's burden in caring for the mentally ill members and growing self-help movement of the families of mentally ill.

#### The objective of the present study was,

- ❖ To assess the level of family burden among the care providers of client with schizophrenia.
- ❖ To associate the level of family burden with the selected demographic variables of the care providers of client with schizophrenia.

## MATERIALS AND RESEARCH METHODOLOGY

A non-experimental research design and descriptive approach was adopted to assess the level of family burden among the caregivers of schizophrenic patients at the Kongunadu Mananala Arakkattalai in Coimbatore. The demographic characteristics of the caregivers, such as age, gender, relationship, marital status, religion, education, occupation, income, area of residence, and health issues, as well as their level of burden of care giving were analyzed in this study. It included 100 caregivers of schizophrenic patients, selected through non-probability purposive sampling technique based on the inclusion and exclusion criteria.

#### Inclusion Criteria

- Caregivers who were in the age range of 20 to 60 years;
- Taking care of a family member diagnosed with schizophrenia for more than a year and
- Whose patients were under medication and had regular follow-up.
- Caregivers who had: patients with co-morbid conditions

#### Exclusion Criteria

- Not been living with the patient for at least 6 to 10 months
- History of medical or psychiatric illness before becoming a caregiver and
- Were not willing to participate in the study.

#### The Study Consisted of Two Sections

**Section A:** Demographic variables of the caregiver – age, gender, relationship with the patient, marital status, religion, area or residence, education, occupation, income, and any past health issues.



**Section B:** Assessment of the level of burden among the caregivers using the standardized questionnaire and the scores obtained from the “Burden Assessment Scale”.

### DATA COLLECTION PROCEDURE

The permission to collect data was obtained from the chief psychiatrist of Kongunadu Mananala Arakkattalai Dhaliyur, Coimbatore before study initiation. Informed consent was obtained from the study participants. The data was collected by the researcher for 4 weeks. All the caregivers were asked to visit the center. Individual pre-tests were done by asking them to provide answers to a standardized questionnaire, and their responses were scored according to the “Burden Assessment Scale,” used to assess the level of burden on families of mentally ill patients. The total number of questions is 20. The levels of burden based

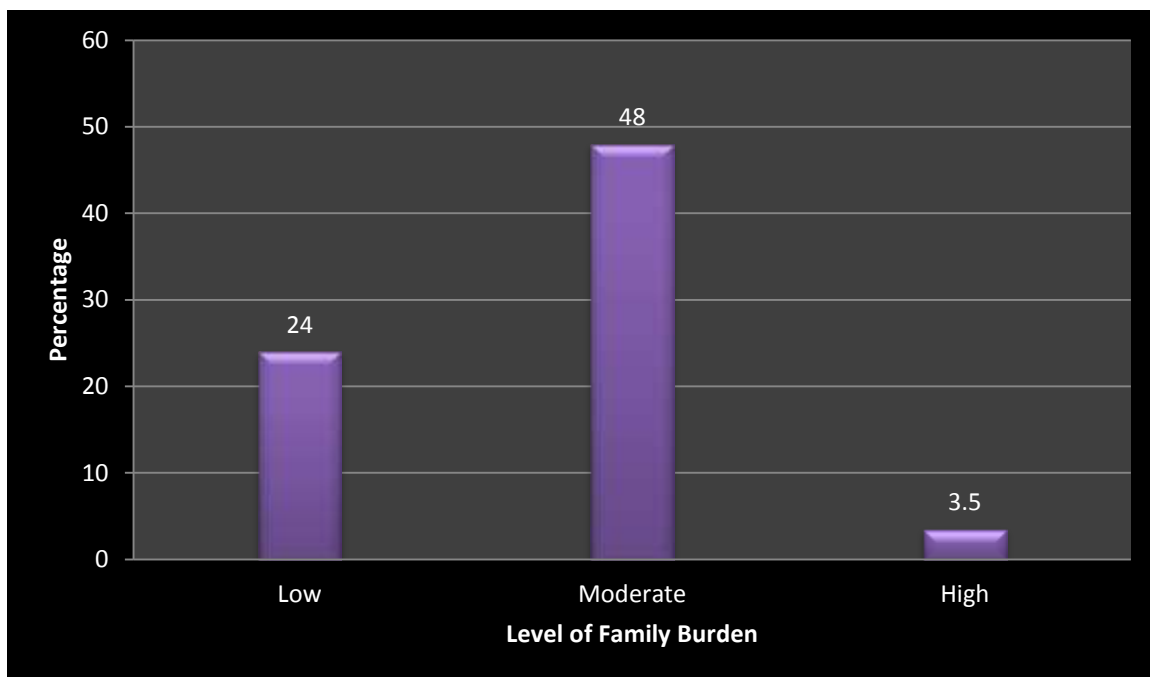
on the scores were categorized as follows: 0-20 (low), 21-40 (moderate), and 41-60 (high).

### ANALYSIS AND INTERPRETATION

Based on the caregivers demographic information, it was noted that: 45 (45%) of them were in the age group of 41-50 years; majority of them were female: 65 (65%); about half of them were married: 60 (60%); most of the caregivers were the spouses of the patients: 68 (68%); one-third of them were Hindu: 64 (64%); half of them resided in rural areas: 57 (57%); many of them had completed higher secondary education: 40 (40%) and were employed: 41 (41%); 43 (43%) of them had an income in the INR 5,000-10,000 per month range; and 61 (61%) of them had no health issues.

**Table 1: Distribution of caregivers according to their level of family burden**

S.No	Score	Level of family burden	Frequency (n)	Percentage (%)
1	0-20	Low	24	24
2	21-40	Moderate	48	48
3	41-60	High	28	28



**Figure:1** Percentage distribution of caregivers according to their level of family burden



It was observed that 24 (24%) of the respondents had low, 48 (48%) had moderate, and 28 (28%) had high level of family burden, respectively. There was no significant association between the caregivers level of family burden and their demographic variables such as age, gender, relationship with the patient, marital status, religion, residential area, education, and health issues; however, it was highly significant for joint family setting, occupation, and the income of the caregiver.

## NURSING IMPLICATION

### Nursing Education

1. Nurses should give attention to improve the knowledge of schizophrenia and its treatment and prevention.
2. Inadequate knowledge will lead to high prevalence of stress and family burden among family care providers of clients with schizophrenia.
3. Therefore the family care providers must be aware of the nature of the disease, its treatment and prevention.

### Nursing Research

1. The study creates awareness for further studies among family care providers of clients with schizophrenia.
2. Further, researcher can use this study as a valuable reference material. Large scale studies can be conducted.

### Nursing Management

Steps should be taken by the higher authorities to organize seminars and workshops for the up gradation of knowledge through skilful training for health professionals.

### Nursing Administration

Classes should be provided for family care providers which will help them how to tackle stress, coping and family burden while caring for clients with schizophrenia.

## RECOMMENDATION

1. A similar study can be conducted on a larger sample using random sampling technique for broader generalization.
2. The same study can be replicated in urban, semi urban and rural settings.
3. A longitudinal prospective study can be carried out to rule out the causes of stress, family burden and coping among family care providers of clients with schizophrenia.

4. Interventional studies may be carried out on larger sample.

## Limitations of the study

The study was limited for the following reasons:

- It was restricted to caregivers of schizophrenic patients
- The sample size was limited to 100 caregivers
- The data was collected only from first-degree relatives of schizophrenic patients.

## CONCLUSION

The majority of caregivers of schizophrenic patients had moderate level of family burden. Certain social traits such as living in joint families can increase the risk of caregiver burden. There is a need for providing psychological assistance to the vulnerable caregivers to help reduce their burden and employ positive coping strategies, as well as strengthening and increasing the economic support for families affected due to schizophrenia.

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