

Study of Burden Among Caregivers of Patients with Psychiatric Disorders

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Abstract

Introduction: The major issues faced in India regarding mental health are lack of mental health workforce, financial aid, stigma and caregiver burden. Family members are the primary caregivers of the persons with mental illnesses in most of the non-western world. This demand can cause significant stress for caregiver. This study tries to investigate the burden of caregiver of psychiatric patients.

Aims and objectives: The objectives of the study were to assess the level of burden on caregivers and associate it with various demographic variables.

Materials and methods: It is a cross - sectional study of 100 patients. Socio - demographic profile and Zarit Burden Interview were used to assess the data.

Results: The research was conducted with the enrolment of 123 candidates with response rate of 81.30%. Among these, 13 did not give consent and 10 dropped out. This resulted in a total sample of 100 caregivers of patients. Maximum belonged to the age group of 30-40 years. The mean age was 36.32± 3.62 years. Majority of the caregivers were FEMALES (62%) and 38 % were males. About 83% were married followed by 17% who were single or separated. Among relationship of caregivers with the patient, maximum were spouses (43%); husbands (35%) and wives (8%) of the patients. The maximum caregivers were those who had average duration of care giving less than 5 years i.e., 62%. 38% caregivers had spent greater than 5 years.

Keywords: Caregiver burden, Mental health, Illness, stress, Zarit burden interview, Psychiatry.

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Introduction

Mental illness is described as the abnormal change in one's thinking, feeling, memory, perception, and judgment which produce disharmony in person's ability to meet human needs effectively. Around 450 million people worldwide are suffering

from some mental or behavioural disorder according to the WHO, of which schizophrenia, bipolar disorder, depression, and alcohol use disorders are important causes for years lived with disability. [1]

According to the evidence available, in India, about 190–200/1000 population have a psychiatric or mental disorder, this accounts for about 20% of the whole population. The major issues faced in India regarding mental health are lack of mental health workforce, financial aid, stigma, and caregiver burden. [2] A caregiver has been defined as “a family member, who has been staying with the patient for more than a year and has been closely related with the patient's daily living activities, discussions, and care of health.” [3] Family members are the primary caregivers of persons with mental illnesses in most of the non-western world. In India, more than 90% of patients with chronic mental illness live with their families. [4,5]

These demands can bring significant level of stress for caregiver and can affect their overall quality of life, including work, socializing and relationship. As stress is everyday wear and tear on the body it challenges or exceeds one's adaptive resources. Stress has been identified as a 20th century disease and has been viewed as a complex and dynamic transaction between individuals and their environments. [6] Hence, given that the caregiver is crucial to maintaining the patient, understanding, prevention and treatment of the care burden, particularly health-threatening problems, among caregivers may help to reduce the need for hospitalization of patients or, at least, increase the time between admissions. [7] Therefore, the burden of the caregiver is a multidimensional concept, [8] which can be classified in two categories of objective and subjective burdens. The objective burdens are the outward consequences such as downturn of financial resources or disruption in family life and the activities related to provide care for SCI people, 16 which are obviously visible to the others. The subjective burdens are the psychological consequences such as emotional stress or depression 3 reported by

caregiver based on personal appraisals of care-giving experience. [9]

The process of coping is a very complex response that occurs when an individual attempts to remove stress or a perceived threat from the environment. Coping mechanisms help to change cognitive and behavioural effort to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person.

Therefore, we need to educate the caregiver about the cause, course, and prognosis of the disorder. This will help in the better recovery and in avoiding the dropout rates of the patient's treatment. By evaluating the impact of burden on the caregivers, we can provide better psychosocial support to the patient which can help in refining the quality of services provided. Keeping these issues related to burden of family members in mind, the study was planned with the aims to study the sociodemographic profile, the caregiver burden of the caregivers of the patients with different psychiatric illness.

The study tried to investigate the caregiver's stress of psychiatric patients and coping mechanisms used by them. The objectives of the present study were to:

1. Assess the level of burden on caregiver's of psychiatric patients.
2. Associate caregiver's burden with selected demographic variables.

Materials and Methods

It is a cross-sectional study. This study included 100 patients. The caregivers of patients, fulfilling the diagnostic criteria of psychiatric disorder according to International Classification of Diseases-10[10] were included. The attendants with a past history of comorbid psychiatric disorder, not staying with the patient during the period of illness and were noncooperative and nonreliable were excluded from the study.

The present cross-sectional study was conducted in a private tertiary care Centres

located in Jammu and Kashmir. Primary caregivers, male or female, who were able to read and write English or Hindi and were closely associated with the patient's daily activities were included in the study.

Convenience sampling technique was used to obtain the sample. Appropriate ethical clearance was obtained from the Institutional Ethics Committee of a tertiary care hospital and measures were undertaken to maintain confidentiality of caregivers throughout the study and also during the analysis of data. All participants were fully informed about the purpose of the study. Written informed consent was obtained from each participant after the consent form was read by the participants. The consent form was in Hindi and in English, and it stated that the participation was completely voluntary and that the participant could withdraw at any time from the study. Confidentiality was maintained throughout the study.

Inclusion criteria:

- Age (of the attendant) should be more than 18 years.
- Attendants who gave informed consent
- Caregivers who were attending psychiatry OPD of ASCOMS and hospital.
- Caregivers those who are able to communicate in Hindi/English.

Exclusion criteria:

- Caregivers who are not willing to participate in the study.
- Caregivers who are not present during data collection.
- Those with a known diagnosis of mental illness and caregivers who were home nurses were excluded from the study

Study tools

Socio demographic data

This arranged format was used to assess the variables of sociodemographic profile such as sex, age, marital status, religion, income, locality, and type of family.

Zarit Burden Interview (ZBI) The ZBI-22 (Table 1) consists of 22 items scored in 5-point Likert scale from 0 (never) to 4 (nearly always), except for the final item on global burden, rated from 0 (not at all) to 4 (extremely).

The total score ranges from 0 to 88 with higher scores indicating higher burden. In addition, several short forms of the ZBI-22 have been proposed as a rapid screening tool, which are scored according to the same principle as the original ZBI-22.

Statistical Analysis

Descriptive analysis was enumerated by using standard deviation and mean, for variables such as clinical parameters and sociodemographic profile. Data were assessed with reference to percentages and frequency for intermittent clinical records and sociodemographic data. Nonparametric tests (e.g., Chi-square etc.) for comparing the variables distinct in nature will be employed. Kruskal Wallis and Mann–Whitney U test was used to find out the total burden score scores of caregivers of different psychiatric groups and to compare the burden among caregivers of same.

Result

The research was conducted with the enrolment of 123 candidates with response rate of 81.30%. Among these, 13 did not give consent and 10 dropped out. This resulted in a total sample of 100 caregivers of patients. Maximum belonged to the age group of 30-40 years. The mean age was 36.32 ± 3.62 years. Majority of the caregivers were FEMALES (62%) and 38 % were males. About 83% were married followed by 17% who were single or separated. Among relationship of caregivers with the patient, maximum were spouses (43%); husbands (35%) and wives (8%) of the patients. The maximum caregivers were those who had average duration of care giving less than 5 years i.e., 62%. 38% caregivers had spent greater than 5 years.

Majority caregivers had mild to moderate burden while severe was present in only 5

% care givers. Most of these caregivers had patients who were neurotic.

Table 1: Age groups of the caregivers

| Age | Number of caregivers | χ^2 | p |
|-------|----------------------|----------|-------|
| 20-30 | 12 | 20.009 | 0.018 |
| 30-40 | 32 | | |
| 40-50 | 24 | | |
| 50-60 | 18 | | |
| 60-70 | 14 | | |

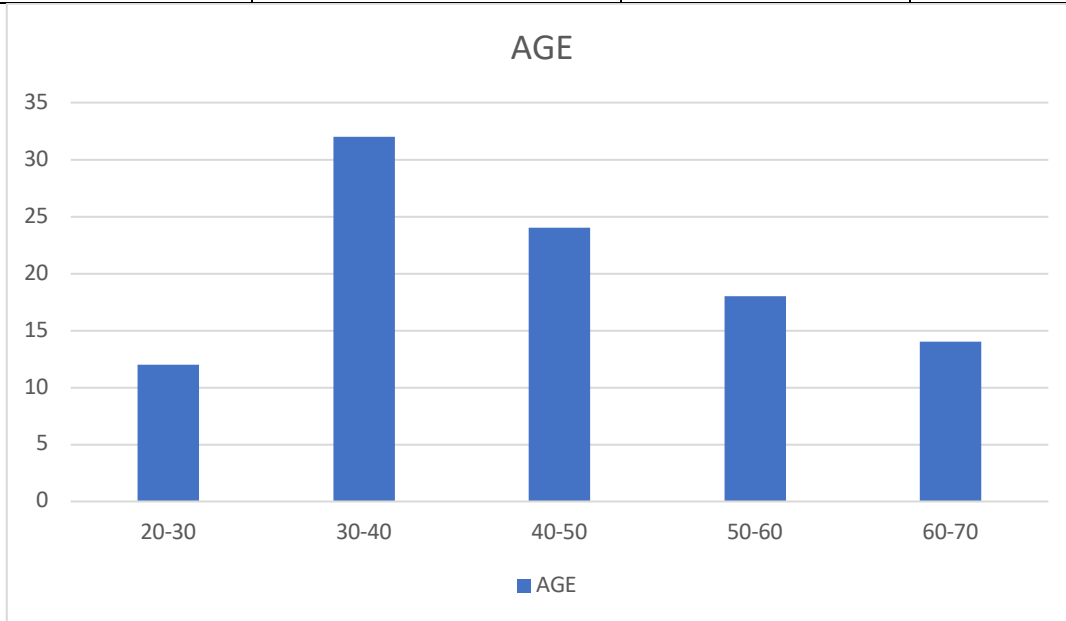


Figure 1: Age groups of the caregivers

Table 2: Gender of the caregivers

| Gender | Number of caregivers | χ^2 | P |
|--------|----------------------|----------|-------|
| Male | 38 | 9.908 | 0.019 |
| Female | 62 | | |

Table 3: Relationship of the caregiver with the patient

| Relationship | | χ^2 | P |
|--------------|----|----------|-------|
| Mother | 12 | 45.577 | 0.001 |
| Father | 11 | | |
| Daughter | 2 | | |
| Son | 15 | | |
| Brother | 7 | | |
| Sister | 10 | | |
| Husband | 35 | | |
| Wife | 8 | | |

Table 4: Marital status of the caregiver

| Marital Status | | χ^2 | P |
|--------------------|----|----------|-------|
| Single / Separated | 17 | 13.321 | 0.149 |
| Married | 83 | | |

Table 5: Level of burden (ZARIT BURDEN INTERVIEW)

| Level of Burden | |
|--------------------|----|
| Little or no | 26 |
| Mild to Moderate | 56 |
| Moderate to Severe | 13 |
| Severe | 5 |

Table 6: Level of burden among caregivers of patients with diagnosis as neurosis , psychosis or substance abuse

| Level of burden | Neurotic | Psychotic | Substance Abuse | χ^2 | P |
|--------------------|----------|-----------|-----------------|----------|-------|
| Little or no | 18 | 3 | 5 | 21.737 | 0.010 |
| Mild to Moderate | 30 | 16 | 10 | | |
| Moderate to Severe | 6 | 4 | 3 | | |
| Severe | 2 | 1 | 2 | | |

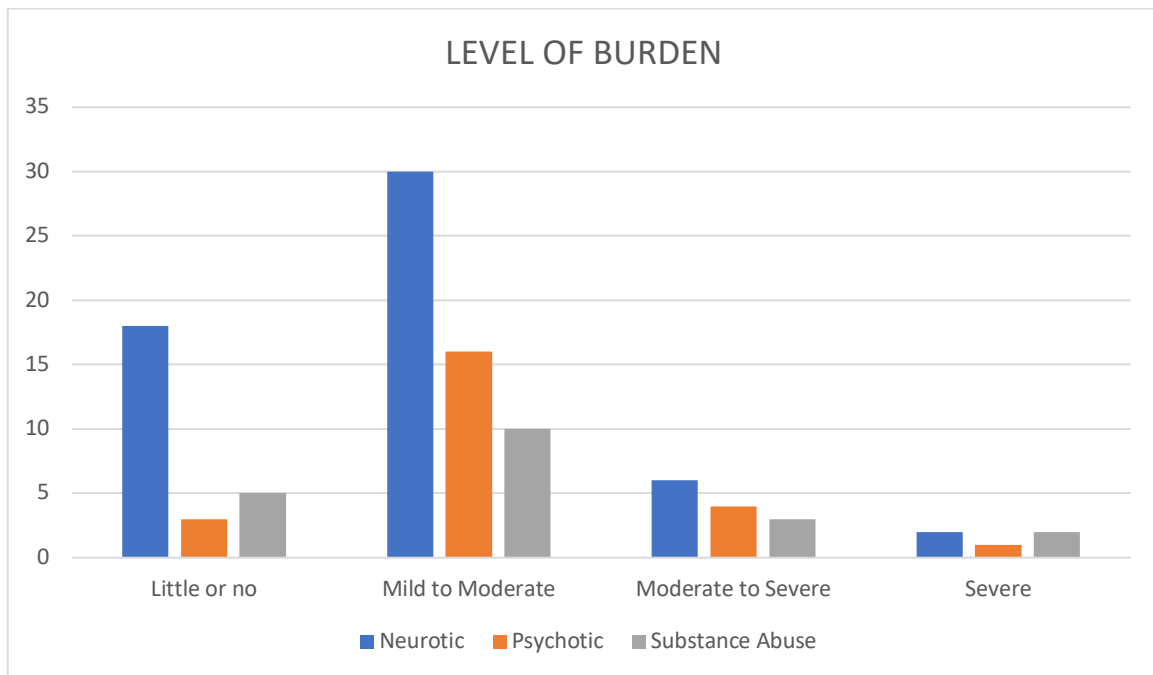


Figure 2: Level of burden (ZARIT BURDEN INTERVIEW)

Table 7: Duration of care giving

| Duration | Number |
|----------|--------|
| <5 | 62 |
| >5 | 38 |

Discussion

In previous study, it has been observed that maximum number of the caretakers (34%) were of the age group 42–54 years not favouring our study. No specific reason was found but might be because of the regional variation.

Some of the previous studies supported our findings in which majority [11] of the

caregivers (62%) were females, also in another study, [12] male caregivers were the maximum. Maximum were male in a previous study contradicting our findings. [13] Out of total, 57 were females in a study by Yazici *et al.* [14] favouring our results. Since, males are the majority working population so the females remain the caregiver who can give more time to the patients, that may be the reason for more

females as caregivers. Furthermore, males are the earning members, hence do not accompany the patients alone.

In a previous study,[13] about 40% of the caregivers were spouses of the patients in conformity to our study. In a study Molebatsi *et al.* [12] it was found that majority of the study participants were mothers (72.2%), while in our study, maximum were spouses. Furthermore, in another study, maximum caregivers were parents, contradicting our findings. [15] The reason of this difference can be that we included different disorders groups, whereas in the other studies mostly only one group was included as the sample.

Maximum caregivers had mean score of moderate-to-severe caregiver burden; (39.7%) in a previous observation [12] differing our results. In another study, the mean score of ZBI came out to be 27.66 (mild to moderate) like our findings. [15] About 49% of caregivers had high burden opposing our observation. Furthermore, supporting our results showing the mean score of ZBI was 24 lying in the group of mild-to-moderate burden level. [16] While in a study by Lasebikan and Ayinde, [17] it was reported that parents (81.5%) were maximum of all followed by spouses (11.7%). In this study, caregivers of only schizophrenic patients were included, which are less likely married and hence accompanied by the parents.

In a previous study by Shamsaei *et al.* [18] the result showed that most of the population (41.8%) experienced moderate-to-severe burden and 7.6% experienced “no to low” burden, 23.5% “mild to moderate,” and 27.1% “severe” burden. The severity of burden is different because the sample population in the above study were patients with schizophrenia only, whereas we had four different groups of patients with different diagnosis. In another study, [19] wives of both alcohol and heroin-dependent patients had moderate-to-high burden of caregiving (mean score of 38.1) opposing

our findings, may be because of the difference in the diagnosis of the patients included. According to the study by Solanki *et al.*, [20] the burden and attitude of schizophrenic patients’ caregivers were statistically significant ($P \leq 0.001$) supporting our results which observed a significant association with the level of burden.

A significant association was seen with severe burden found in psychotic disorder group than the mood disorder group. This was supported by a study by Parija *et al* [21] in which there was a significantly higher total burden in caregivers of patients with schizophrenia (psychotic disorder) compared to bipolar affective disorder (BPAD) (mood disorder) and the $P = 0.01$. Another study by Bora and Das [22] favoring our findings reported that the mean burden score for chronic schizophrenia group was 102.86 ± 27.04 , whereas the mean BAS score for the BPAD group was 88.80 ± 22.31 . Caregivers of chronic schizophrenia experienced significantly higher burden than the caregivers of BPAD ($P = 0.03$).

Conclusion

We concluded that the relationship of the caregiver with the patient has a positive impact on the burden of the caregiver. The maximum burden level was mild-to-moderate level. A significant association was seen with the level of burden.

Limitations

We did not study many other psychosocial variables, such as social support, disability, coping skills, involvement in patient care, accommodation and QOL of patients, etc., which could influence the perceived burden. Duration of caregiving and the sociodemographic details of the patients, if included would have made the study more authentic. Future studies should try to address these issues.

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