

Section **Psychiatry**

**Original** Article

## A Study on Assessment of Family Burden, Quality of Life and Mental Health in Caregivers of Patients with Schizophrenia

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### ABSTRACT

**Background:** Caregivers of patient with schizophrenia face a lot of burden which hampers their quality of life as well as mental health. This study was conducted to evaluate perceived burden of care, quality of life, and mental health in caregivers of schizophrenia patients and to explore the correlation between above parameters and total duration of illness of the patient with schizophrenia.

**Methods:** The study was conducted at a tertiary care center. Participants were 99 caregivers of the patient with schizophrenia that were screened to ascertain whether they met the selection criteria. Perceived burden was scored by Family burden scale which is a semi structured interview schedule. Quality of life scale (WHO QoL-BREF Hindi version), was used to assess Quality of life. Modified Mini International Neuropsychiatric Interview was used to examine mental health of caregivers. **Results:** In the present study, total duration of schizophrenia showed statistically significant negative correlation with quality of life of caregiver. In the study, though the correlation between perceived family burden and total duration of schizophrenia was positive but it was not statistically significant. The burden also had statistically significant negative correlation with socioeconomic status and quality of life of the caregiver. The caregivers with high likelihood of mental illness scored significantly higher burden than other two groups. **Conclusions:** Caregivers of persons with schizophrenia do perceive burden, on account of which and along with lower socioeconomic status they experience poor quality of life and compromised mental health.

**Key words:** Burden of care, Schizophrenia, Quality of life, Duration of illness, Mental health.

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### INTRODUCTION

Schizophrenia is a debilitating psychiatric disorder which not only influences the lives of those affected but also of their families. Schizophrenia is ranked among the top 25 leading causes of disability worldwide in 2013.<sup>[1]</sup> Of all the mental illnesses responsible for suffering in society, schizophrenia probably causes lengthier hospitalization, more chaos in family life, exorbitant costs to individuals and

governments and fears than any other illness.<sup>[2]</sup>

In the past few decades, a shift towards community care and the deinstitutionalization of psychiatric patients has resulted in transferring of responsibility and day-to-day care of such patients to family members.<sup>[3]</sup> Families are thus assigned the role of primary caretakers for two reasons. First, there is a

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paucity of trained professionals required to execute psychosocial interventions and second, most Indian families would like to be meaningfully involved in all aspects of care of their ill relative.<sup>[4]</sup> Caregivers have to deal with patient's symptoms, and help patients in activities of daily living.

The caregiver is seen as the person who provides the most support to the patient, often devoting substantial number of hours each day towards taking care of the patient.<sup>[5]</sup> Caregivers spend a substantial amount of time interacting with their care recipients, while providing care in a wide range of activities. The patient's illness, behaviors, disabilities and perceived disruptions of the caregivers' lives are the stressors appraised by the caregivers.<sup>[6]</sup> The behavior of the patients with schizophrenia requires that the caregivers place their needs and wishes after those of their wards; consequently, the phenomenon has been labeled as a burden.<sup>[7-10]</sup> It refers to the presence of problems, difficulties or adverse events which affect the lives of caregivers.

There are stressful effects on the caregivers' own mental and physical health, like the feelings of stigmatization, inability to make or fulfill personal plans, empathic suffering for the pain of the ill member, worries for the ill member's future, especially if he/she is young. The behaviors of the patients and their management are issues that create ongoing tensions between the patients and their families.<sup>[11]</sup>

In India, care for other family members is an obligation and all caregivers perceive the burden. Providing care to a person with schizophrenia is often consistent and ongoing for long periods; and the role of the caregiver is stressful. The physical, mental and emotional toll of caregiving can be devastating and may lead to injury or illness of the caregiver.<sup>[12-16]</sup>

The stresses of caring for a relative with schizophrenia might lead to poorer quality of life and greater chances of physical and mental illness. Greater degree of depression and stress and low rating of subjective well-being in caregivers has been reported.<sup>[17-19]</sup>

The present study examines the caregiving burden and its correlates in primary caregivers of a patient with schizophrenia. This study aimed to evaluate perceived burden of care, quality of life, and mental health in caregivers of schizophrenia patients and to explore the correlation between above parameters and total duration of illness.

## METHODS

A cross sectional observational study was carried out on caregivers of schizophrenia patient. Study was approved by research review board and ethical committee of the institution. The study included 99 caregivers of patients (The diagnosis was reviewed and confirmed by two psychiatrists independently based on ICD-10 criteria). An informed consent was obtained from the subjects prior to participation in the study. To include in study, the subjects were screened with a screening proforma that encompassed all the exclusion criteria. Those subjects who satisfied the screening process were recruited in the study. An informed consent was

obtained from the patients and caregivers prior to participation in the study. This was followed by recording of socio-demographic profile and clinical profile. Each participant in the study was subjected to instruments of the study. This was followed by statistical analysis with the help of computer.

The study was conducted in the Department of Psychiatry, SMS Medical College, Jaipur which a tertiary care center. The study was conducted from 1st January 2012 to 31st December 2012. Family members of the patient attending the OPD or IPD were included in this study. They were screened by history to ascertain whether they met the selection criteria. Inclusion criteria: Patients of either gender aged 18-60 years having diagnosis of schizophrenia as per ICD-10 criteria, total duration of illness at least one year, who were living with a caregiver / family member for at least one year and provided informed consent; were included in the study.

Caregivers of either gender, aged 18-60 years, who were responsible for patient's care, living with the patient for at least one year and were spending more time with the patient than other family members, who were literate enough to read and understand the questionnaires and provided informed consent; were included in the study.

Exclusion criteria: Patients having a serious physical disability and Mental retardation were excluded. Caregivers with a physical disability (e.g. blind, deaf, speech problems), diagnosed psychiatric disorders, mental retardation and dementia, abusing substance other than nicotine, having color blindness; were excluded.

The subjects were interviewed after examination using the following instruments-

1. Consent form: This form was in Hindi language and was given before including the subject in study. The informed written consent was taken from each subject.
2. Socioeconomic status score was assessed using modified kuppuswamy scale for socioeconomic status.
3. Family Burden scale:<sup>[20]</sup> This is a semi structured interview schedule comprising of 24 items grouped under these areas: financial burden, disruption of routine family activities, disruption of family leisures, and disruption of family interaction, effect on physical health of others and effect on mental health of others. The burden is rated on a 3- point scale for each item, and a standard question to assess the subjective burden is also included. This scale has been developed for the Indian set up, keeping in the mind the socioeconomic and cultural conditions in the India. The validity and reliability of the scale have been found to be satisfactory. The interrelated reliability for each item was reported to be more than 0.78 by the authors, which indicates that the present schedule is a reliable tool.
4. Quality of life scale (WHO QoL-BREF version): <sup>[21]</sup> An abbreviated version (WHOQOL-Bref, Hindi) of 26 items is developed using data from the field-trial version of the WHOQOL- 100. The WHOQOL-Bref contains two items from the overall QOL and general health, and one item from each of the remaining 24 facets included in the WHOQOL-100. This scale provides a profile of scores on four dimensions

of quality of life: physical health, psychological, social relationship, and environment. Its 26-items look at domain level profiles and are self-administered. Higher scores mean higher quality of life.

5. Modified mini International Neuropsychiatric Interview (MINI) (22): It is a 22 item questionnaire that is administered by a clinician in about 15 minutes. The tool uses a set of gateway questions that relate to signs of distress that may be attributable to a diagnosable psychiatric disorder. The screen is divided into 3 sections to capture the three major categories of mental illness as follows: Section A- Mood Disorders, Section B-Anxiety Disorders, and Section C- Psychotic Disorders. Scoring of the Modified Mini Screen is straightforward and additive. A "YES" response to a question on the screen converts to 1 point. The clinician adds all the positive (yes) responses for a total score, which ranges from 1 to 22 points. There are three different cut points and each cut point determines a different plan of action for the client. CUTPOINT 1 is score  $\leq 5$ . No further action is needed. This plan of action is based only on the screen, but a screening tool should never replace clinical judgment and critical observations by staff.

CUTPOINT 2 is between 6 and 9. The treatment team determines whether there is a need for a mental health assessment. If it is determined that a mental health assessment is not required, enhanced ongoing monitoring for mental health needs will be implemented as part of the initial comprehensive treatment plan. If it is determined that a mental health assessment is needed, action proceeds as listed below for CUTPOINT 3.

CUTPOINT 3 is any one of the following: - Adults who scored  $\geq 10$  or adults who answered "yes" to question 4 or Adults who answered "yes" to both questions 14 and 15. For cut point 3, the client will receive a mental health assessment, which means an evaluation to determine whether a client has unmet mental health needs and includes recommendations for treatment or further evaluation if indicated. Question 4 relates to suicidality. Any client who answers YES to this question should be referred for a mental health assessment regardless of the total score. Questions 14 and 15 refer to Post Traumatic Stress Disorder (PTSD). PTSD does not only address combat/war, but also addresses experiences of physical and sexual abuse, as well as other trauma. If both questions 14 and 15 are answered YES, the client should be referred for a mental health assessment regardless of the client's total score.

#### Data analysis

Statistical analysis was done with the help of computer. Quantitative data was expressed as frequencies and quantitative data as mean and standard deviation. Group comparisons for quantitative data were done with the help of non-parametric test i.e. Independent-Samples Kruskal-Wallis Test as the data did not have normal distribution and homogeneity of variance. Further group differences were obtained with the help of post-hoc analysis (group-wise comparisons). Correlations were computed by Pearson's correlation analysis.

## RESULTS

The sample in present study comprised of 99 subjects. Table 1 shows socio-demographic and clinical variables of patients and caregivers and mean scoring on the three scales.

**Table 1: Socio-demographic, clinical variables of patients and caregivers and scoring on the three tools:**

| S. No. | Variable   | Details  |
|--------|--|--|
| 1.     | Patient's age  | 22 to 65 years (Mean =39.68, SD=12.06)                                     |
| 2.     | Patients gender                                      | Male = 69<br>Female = 30   |
| 3.     | Patients marital status:                             | Married = 90<br>Unmarried = 9  |
| 4.     | Total duration of illness of patient                 | 1-30 years (Mean= 10.08, SD= 7.06)   |
| 5.     | Caregiver's age                                      | 18-56 years (Mean=32.66, SD=11.81)   |
| 6.     | Caregiver's gender                                   | Male = 86<br>Female = 13   |
| 7.     | Mean family burden total score of the sample         | 36.35 (SD=10.67)   |
| 8.     | Mean Quality of life total score of the sample       | 70.48 (SD=15.58)   |
| 9.     | The number of caregivers in Modified MINI cut-points | Cutpoint 1: 29 (29.3%)<br>Cutpoint 2: 24 (24.2%)<br>Cutpoint 3: 46 (46.5%) |

SD=Standard deviation

Table 2 shows that of total duration of illness is inversely correlated with the quality of life score, and is directly correlated with the family burden score.

**Table 2: Correlations of total duration of illness with family burden and Quality of life**

|     | FBS Score           | QoL score    |
|-----|---------------------|--------------|
| TDI | Pearson Correlation | 0.025        |
|     | Sig. (2-tailed)     | 0.808        |
|     |                     | <b>0.014</b> |

TDI= total duration of illness, FBS= Family burden scale, QoL= Quality of life

Table 3 shows family burden total score is negatively correlated with both socioeconomic status score and quality of life total score.

**Table 3: Correlations of family burden with socioeconomic status and quality of life**

|     | SES Total score       | Total QoL Score |
|-----|-----------------------|-----------------|
| FBS | Pearson's Correlation | -0.210          |
|     | Signi. (2-tailed)     | <b>0.037</b>    |

FBS= family burden scale, SES= socioeconomic status, QoL= quality of life

Table 4 (a) shows Independent Sample Kruskal-Wallis test for Family Burden Scale Total score and table 4 (b) shows its further Post hoc analysis.

**Table 4 (a): Independent Sample Kruskal-Wallis test Family Burden Scale Total score**

| Sample (N)           | Mean(SD)    | Test statistics | df | Asymptotic value |
|----------------------|-------------|-----------------|----|------------------|
| MINI Cutpoint 1(29)  | 29.59(11.6) |                 |    |                  |
| MINI Cutpoint 2 (24) | 35.17(10.7) | 20.6            | 2  | 0.00             |
| MINI Cutpoint 3 (46) | 41.24(7.5)  |                 |    |                  |

N= number, SD= Standard deviation, df= degree of freedom

**Table 4 (b): Post hoc analysis**

| Sample            | Test statistic | Std. error | Std.test statistic | Sig.  | Adj.sig |
|-------------------|----------------|------------|--------------------|-------|---------|
| MINI Cutpoint 1-2 | -12.7          | 7.9        | -1.6               | 0.10  | 0.323   |
| MINI Cutpoint 1-3 | -30.3          | 6.8        | -4.4               | 0.00  | 0.000   |
| MINI Cutpoint 3-2 | -17.5          | 7.2        | -2.4               | 0.015 | 0.045   |

## DISCUSSION

In the present study, total duration of schizophrenia showed statistically significant negative correlation with quality of life of caregiver. In the study, though the correlation between perceived family burden and total duration of schizophrenia was positive but it was not having statistical significance. The burden also had statistically significant negative correlation with socioeconomic status and quality of life of the caregiver. The caregivers with high likelihood of mental illness scored significantly higher burden than other two groups.

The duration of caregiving did not vary significantly with the total burden score in the study, which emphasizes that longer (after one year) periods of caregiving did not necessarily result in greater caregiver's burden. The trend is that prolonged caregiving does not result in increased burden or psychological distress. It is seen that with increasing duration of patient's illness, the family tends to adjust its ways and means according to patient's illness and hence, burden felt is not as much as expected. This finding is consistent with other studies.<sup>[1]</sup> also found that the duration of illness of the patients did not correlate with the carers' burden or needs. McDonnell et al.<sup>[26]</sup> also reported that duration of the illness was not a significant independent predictor of burden. Contrary to our findings, total burden was found to be significantly more if duration of illness was more.<sup>[27]</sup> Leyla et al.<sup>[28]</sup> also observed that the burden of care was positively correlated with the total duration of illness. Total duration of illness had significant negative correlation with quality of life score. ZamZam et al.<sup>[29]</sup> also reported that less duration of illness was significantly associated with higher scores in all domains of the caregivers' Quality of life. So it is suggested that the threatening nature of positive symptoms and more negative symptoms of schizophrenia make the patient more intolerable to caregivers as the illness becomes more chronic. Sales.<sup>[30]</sup> also reported that caregivers have poor quality of life as they are burdened and

strained for long duration. The chronic burden of everyday living profoundly reduces the quality of life and declines satisfaction.

In the present study, family burden score had negatively significant correlation with both socioeconomic status and quality of life scores. Besides providing care for ill member, caregivers also have to solve financial problems and find out sources of money. Family burden in caregivers of patients is a disability related to work, participation in household duties and lack of self-care, satisfaction with mental health services, and social relationships, nuisances, and burden due to restricted social life and leisure activities, worries about the patients' health, future, and safety. Other studies.<sup>[31,32]</sup> also found supporting results. Two studies.<sup>[33,34]</sup> also showed that low income was associated with a higher degree of burden on the caregivers. Lower income is a stressor that influences perception of caregiver's burden while providing care for the ill family member.

As per modified MINI groups (according to Cutpoint 1-3), these groups differed significantly in the mean of burden score and it was found that more caregivers fall in high likelihood of mental illness group (cutpoint-3) and this group scored significantly higher burden than other two groups. Aydin et al 2009 also reported that as the burden of care increased, the level of anxiety and depression in caregivers also increased. Similar to our study, Noh and Turner.<sup>[35]</sup> also reported that burden was a major source of stress. Lowyck et al.<sup>[36]</sup> also concluded that key relatives taking care of the patient do experience an ample amount of burden, on both a practical and emotional level; and the number of the symptoms exhibited by the patient was an influence on family burden.

## CONCLUSION

In this study, the authors found that the duration of schizophrenia does not significantly influence the level of burden but it does significantly affect the quality of life. The caregivers of lower socioeconomic status perceived higher family burden and have poor quality of life. The caregivers with higher family burden also showed significantly higher likelihood of developing mental illness. Though it was a cross-sectional study with small sample size, but it can be a directive for future case control studies that may be done on longitudinal basis with large sample sizes to allow generalization of the significant findings and promote holistic management of families harboring person with chronic mental illness.

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