A study of psychological distress in caregivers of schizophrenia patients
Prathyusha Mikkilineni1, Sabari Sridhar. O.T2, B Srinivasan3, Kailash S4
1Final Year Post-graduate, 2Associate Professor, 3HOD, 4Assistant Professor, Dept. of Psychiatry, Chettinad Hospital and Research Institute, Tamil Nadu, India
*Corresponding Author: Sabari Sridhar. O.T Email: prathyu16mikkilineni@gmail.com

Abstract
Introduction: Mental illness in a family member can be a huge burden and problematic on the care givers and family. The study was conducted with the aim of assessing the psychological distress and caregiver burden among care givers of schizophrenia patients.

Materials and Methods: In this cross-sectional study, detailed history, relevant sociodemographic details, clinical and psychological assessment findings were documented in a structured proforma in all the subjects. Burden assessment schedule (BAS) was administered to assess caregiver burden, Self-reporting questionnaire 20 (SRQ 20) to assess psychological distress among the caregivers and Positive and Negative symptom scale (PANSS) for severity of symptoms in schizophrenic patients.

Results: A total of 40 subjects were included in the study. The mean age of the study population was 44.08 ± 12.12, 12(30%) participants were males and 28(70%) were females. The mean total caregiving time of study population was 7.63 ± 2.37 with the range 3 to 12 hours/days. 15 caregivers (37.50%) had psychological distress, and 25(62.50%) had no psychological distress. On univariate analysis, age, caregiver burden, total caregiving time (hours/day), negative symptoms and total PANSS score were found to be significantly associated with psychological distress among caregivers. After adjusting for the effect of other variables in the equation, it was found that the odds of psychological distress increased 1.09 times (95% CI 1.108 to 1.186, P value 0.015) with one unit increase in severity of caregiver burden.

Conclusion: The most important predictive factor of psychological distress in caregivers was the severity caregiving burden.

Keywords: Family, Caregivers, Psychological stress, Schizophrenia.

Introduction
Presence of mental illness in a family member can put a huge burden on the caregivers and family members and may lead to not only psychological distress and also physical illness.2 Schizophrenia is one such psychiatric illness, which is reported to result in heavy burden and psychological distress in various settings.2-3 Many studies conducted in the community, outpatient and inpatient care settings across the globe have documented high levels of caregiver burden, different types of negative psychological impact.4-10 The typology of schizophrenia and the duration of illness were proved to be one of the strong correlates of the high caregiver burden in earlier studies.11-14

It is highly important to understand various disease-related and caregiver-related factors associated with psychological distress to be able to develop appropriate interventions to minimise the burden and associated distress. But a huge variation in the methodology and instruments used precludes effective cross-study comparison.5

There are very limited numbers of studies available on the subject in the Indian population. Jagannathan, A. et al.15 have reported the duration of illness and perceived social support to be significant predictors of burden in addition to psychopathology and disability. Kumar, C. N., et al.16 have concluded that burden experienced by family caregivers of schizophrenia patients depends on the level of disability experienced by the patient, age of the family caregivers and gender of the patient. Interventions to reduce disability of the patients may reduce the caregiver burden.

But, because of wide variations in the tools and methods used to assess the psychological impact and caregiver burden, it is very difficult to draw comparisons between studies conducted in different settings. Also due to huge differences in the stigma, cultural factors and sociodemographic profile of the populations across different settings, it is highly necessary to develop evidence on local populations to be able to develop culture-specific interventions. Hence the current study has been conducted with an objective of assessing the correlates of caregiver burden among caregivers of schizophrenia patients attending a tertiary care teaching hospital in south India.

Objectives
1. To study the prevalence and correlates of psychological distress and caregiver’s burden of patients with Schizophrenia.

Materials and Methods
The current study was a cross-sectional study conducted in the Department of Psychiatry, Chettinad Hospital and research institute (CHRI), Kelambakkam. Primary Caregivers of psychiatric inpatients and outpatients in CHRI, Kelambakkam with a diagnosis of Schizophrenia with duration of illness >2yrs classified under F20 according to ICD-10 and aged more than 18 years were included in the study. Exclusion of caregivers of patients with psychiatric illness other than those under F20 and less than 18 years age was done. After obtaining informed written consent, all the subjects were evaluated by detailed history. Relevant sociodemographic details, clinical and psychological assessment findings were documented in a structured proforma. The following scales were administered:

1. Burden assessment schedule (BAS) -A 40 item questionnaire assessing both the objective and
subjective burden experienced by the caregiver of mentally ill patients. The scores range from 40 to 120.\(^7\)

2. Self-reporting questionnaire 20 (SRQ 20) to assess psychological distress. It is a 20-item mental disorder screening instrument developed by World Health Organization.\(^8\)

3. PANSS (Positive and Negative symptom scale).\(^9\) This consists of 3 dimensions-Positive symptoms, Negative Symptoms and General symptoms to assess the severity of symptoms in patients with schizophrenia.

The study was conducted after obtaining ethical clearance from Institutional Human Ethics Committee. All patients were given necessary treatment irrespective of their caregiver’s participation in the study. In the case of the presence of psychological distress in the caregivers, further evaluation and appropriate management was done.

**Sample size**

Sample size was calculated assuming the proportion of psychological distress among the caregivers as 31.5% as per the study by Hui Chien Ong et al.\(^21\) The other parameters considered for sample size calculation were 15% absolute precision and 95% confidence level. The following formula was used for sample size calculation. The required number of subjects as per the above-mentioned calculation was 37. To account for a non-participation rate of about 10% (3 subjects), it was decided to sample about 40 subjects in the study.

**Statistical methods**

Descriptive analysis was carried out by the mean and standard deviation for quantitative variables, frequency and proportion for categorical variables. Univariate binary logistic regression analysis was performed to test the association between the explanatory variables and psychological distress (Self-reporting questionnaire 20). Unadjusted Odds ratio along with 95% CI is presented. Variables with statistical significance in univariate analysis were used to compute multivariate regression analysis. Adjusted odds ratio along with their 95% CI is presented. P value < 0.05 was considered statistically significant. IBM SPSS version 22 was used for statistical analysis.

**Results**

A total of 40 subjects were included in the analysis.

| Demographic parameter          | Mean/Frequency | SD/Percentage |
|--------------------------------|----------------|---------------|
| **Age (Mean ±STD)**            | 44.08          | ± 12.12       |
| **Gender**                     |                |               |
| Male                           | 12             | 30.00%        |
| Female                         | 28             | 70.00%        |
| **Marital status**             |                |               |
| Married                        | 35             | 87.50%        |
| Unmarried                      | 5              | 12.50%        |
| **Education**                  |                |               |
| Middle School                  | 15             | 37.50%        |
| Primary School                 | 12             | 30.00%        |
| High School                    | 8              | 20.00%        |
| Illiterate                     | 5              | 12.50%        |
| **Occupation**                 |                |               |
| Unemployed                     | 14             | 35.00%        |
| Unskilled Worker               | 13             | 32.50%        |
| Employed                       | 13             | 32.50%        |
| **Family type**                |                |               |
| Joint                          | 5              | 12.50%        |
| Nuclear                        | 35             | 87.50%        |
| **Primary earning member of family** |        |               |
| Caregiver                      | 14             | 35.00%        |
| Patient                        | 13             | 32.50%        |

The mean duration of caregiving of study population was 7 ± 5.87 years with the range of 2 to 30 years. The mean total caregiving time per day of study population was 7.63 ± 2.37 with the range of 3 to 12 hours/days. The mean duration of illness of the patients was 8.8 ± 8.52 with the range 2 to 40 years. Among the schizophrenia patients, 40(100%) had positive symptoms, 22(55%) had negative symptoms and 39(97.50%) had general symptoms. The mean PANSS score of the study population was 57.30 ± 12.74 with the range 36 to 82. The mean caregiver burden schedule score of the study population was 44.60 ± 18.44 with the range of 20 to 80.
Table 2: Univariate logistic regression analysis factors associated with psychological distress in the study population (N=322)

| Parameter                                           | Odds ratio | 95% CI       | P value |
|-----------------------------------------------------|------------|--------------|---------|
|                                                     |            | Lower | Upper |         |             |
| Age                                                 | 1.073      | 1.002 | 1.149 | 0.044  |
| Gender (baseline= Male)                             |            |       |       |         |             |
| Female                                              | 2.250      | 0.499 | 10.143| 0.291  |
| Marital status (baseline = Married)                 |            |       |       |         |             |
| Unmarried                                           | 1.128      | 0.166 | 7.665 | 0.902  |
| Education (base line= Illiterate)                   |            |       |       |         |             |
| Middle School                                       | 2.667      | 0.237 | 30.066| 0.427  |
| Primary School                                      | 2.857      | 0.241 | 33.902| 0.406  |
| High School                                         | 2.400      | 0.175 | 32.879| 0.512  |
| Occupation (baseline= Unemployed)                   |            |       |       |         |             |
| Unskilled Worker                                    | 1.125      | 0.236 | 5.371 | 0.883  |
| Employed                                            | 1.125      | 0.236 | 5.371 | 0.883  |
| Patient primary earning member of the family (Baseline=No) | | | | |
| Yes                                                 | 0.646      | 0.158 | 2.637 | 0.543  |
| Duration of caregiving (in years)                   | 1.148      | 0.995 | 1.324 | 0.059  |
| Total caregiving time (hours/day)                   | 1.392      | 0.018 | 1.904 | 0.039  |
| Duration of illness (in years)                      | 1.044      | 0.966 | 1.129 | 0.279  |
| Type of symptoms                                    |            |       |       |         |             |
| Positive symptoms                                   | 1.044      | 0.966 | 1.129 | 0.279  |
| Negative Symptoms                                   | 1.087      | 1.002 | 1.178 | 0.045  |
| General symptoms                                    | 1.086      | 0.957 | 1.233 | 0.200  |
| PANSS total                                         | 1.083      | 0.017 | 1.154 | 0.013  |
| Care Giver Burden Schedule                          | 1.117      | 1.047 | 1.192 | 0.001  |

The presence or absence of Psychological distress among the study population was determined using Self-reporting questionnaire 20. 15(37.50%) were found to have psychological distress and 25(62.5%) did not have distress. The odds of psychological distress were 1.073 times increase with each year increase age which was statistically significant (P value 0.044). The odds of psychological distress were 1.392 times increasing with each one hour increase in total caregiving giving time which was statistically significant (P value 0.039). The odds of psychological distress in caregivers was 1.087 times more in patients who had negative symptoms compare to those with positive symptoms. The association was statistically significant (P value 0.045). The odds of psychological distress was 1.083 times increased with one unit increase in PANSS total score and was statistically significant (P value 0.013). The odds of psychological distress was 1.117 times increased with one unit increase in Care Giver Burden Schedule score which was statistically significant (P value 0.001). The remaining parameters have not shown any statistically significant association with psychological distress (P value >0.05).

Table 3: Multivariate logistic regression analysis of factors associated with psychological distress (Self-reporting questionnaire 20) (N=322)

| Parameter                     | Adjusted odds ratio | 95% C.I. for the adjusted odds ratio | P value |
|-------------------------------|---------------------|--------------------------------------|---------|
|                               |                     | Lower | Upper   |         |            |
| Age                           | 1.003               | 0.924 | 1.088   | 0.951   |
| Total caregiving time (hours/day) | 1.070             | 0.625 | 1.832   | 0.806   |
| Negative Symptoms             | 0.988               | 1.851 | 1.146   | 0.870   |
| PANSS total                   | 1.060               | 0.962 | 1.168   | 0.237   |
| Care Giver Burden Schedule    | 1.099               | 1.108 | 1.186   | 0.015   |
After adjusting for the effect of other variables in the equation, only one parameter had shown statistically significant association with psychological distress in the study. The odds of psychological distress was increased 1.09 times (95% CI 1.108 to 1.186, P value 0.015) with one unit increase in caregiver burden schedule score.

**Discussion**

**Caregiver characteristics**

The current study which has evaluated the burden of caregivers using Burden assessment schedule (BAS) scale and the presence of psychological distress using Self-reporting questionnaire 20 (SRQ 20) was conducted in a tertiary care teaching hospital in South India. The mean age of the caregivers was 44.08 ± 12.12 years and 70% of caregivers were women. Majority of them were married and studied up to middle school and a major proportion of them were either unemployed or unskilled workers. In more than 50% of the cases, the caregiver was a spouse, and in the remaining cases, it was other family members. More than 80% of the study populations were from nuclear families. In a similar study done by Shah, S. T., et al., the mean age of the caregivers was 45.4±14.25 years, which was in accordance with the current study. Forty-two (84%) caregivers were males, and 8 (16%) were females. Twenty-eight (56%) were uneducated, 16 (32%) had Primary education, 4 (8%) were matriculates and 2 (4%), graduates. Thirty-four (68%) of the caregivers were married 8 (16%) each unmarried and widows/widowers. Thirty-two (64%) were unemployed, and 18 (36%) were employed. These parameters differed slightly from the current study.

**Disease-related characteristics**

Among the study population, the mean duration of the schizophrenia was 8.8 ± 8.52 with the range of 2 to 40 years. The mean duration of caregiving was 7 ± 5.87 years and mean time of care giving per day was 7.63 ± 2.37 hours per day. Among the study population, 40(100%) had positive symptoms, 22(55%) had negative symptoms, and 39(97.50%) had general symptoms. The mean PANSS total of the study population was 57.30 ± 12.74, and the mean caregiver burden schedule of the study population was 44.60 ± 18.44. In the study by Kumar, C. N, et al., the mean (SD) duration of illness was 154.8 (119.5) months. Symptoms were mild at the time of assessment (Mean (SD) total PANSS score = 50.5(23.6)), and they had a Mean (SD) total disability of 4.6 (4.2). In the study by Jagannathan, A., et al., the mean (SD) total burden of the caregivers (excluding spouses of the patient) was 80.02 (11.53), and the mean (SD) total burden of caregivers who were spouses of the patients was 74.94(11.27). The average BAS score was 1.94 (0.31). The mean PANSS (total) score was 58.5 (18.9). These studies were in accordance to ours.

**Impact on caregivers**

In the current study, 22(55%) had the moderate burden, and 18(45%) had a severe burden. The mean score of self-reporting questionnaire 20 of the study population was 8.78 ± 3.98. Among the study population, 15(37.50%) had psychological distress, and 25(62.50%) had no psychological distress. The stress level was assessed by using the Self Report Questionnaire (SRQ-20) with a cutoff score of 9 being taken as stressed. The study findings were similar to the study by Shah, S. T., et al., where 72% had psychological distress, and 14 (28%) had no psychological distress. In our study, 37.50% experienced distress whereas in the study by Shah, S. T., et al., where 72% experienced distress. Which was high compared to the current study. Our study was in accordance with the study by Ong, H. C., et al., where 31.5% of the caregivers experienced psychological distress.

**Factors associated with caregiver burden and distress**

Jagannathan, A., et al., in their study of caregivers of 137 schizophrenia patients found that duration of illness and levels of psychopathology and disability had a significant direct correlation with total burden score; perceived social support had a significant inverse correlation with total burden score. There was a high correlation between psychopathology and disability (r<0.001). Two separate regression analyses, each including total PANSS score (psychopathology) or total IDEAS score (disability) showed that duration of illness and perceived social support were significant predictors of burden in addition to psychopathology and disability.

Kumar C. N., et al., found in their study that level of burden had a significant direct correlation with disability (Pearson’s r = 0.35; p < 0.01) and severity of psychopathology (r = 0.21; p < 0.01). Duration of treatment had an inverse correlation with burden (Pearson’s r = -0.16; p < 0.01). Multivariate analysis revealed that total Indian Disability Evaluation and Assessment Scale (IDEAS) score (Beta = 0.28; t = 4.37; p < 0.01), duration of treatment (Beta = -0.17; t = -2.58; p = 0.01), age of the family caregiver (Beta = 0.15; t = 2.4; p = .02) and gender of the patient (Beta = -0.13; t = -2.1; p = 0.04) were significant predictors of burden. The model including total IDEAS score explained 14% of variance (adjusted R (2) = .139; p < .01). The authors concluded that, Burden experienced by family caregivers of schizophrenia patients depends on the level of disability experienced by the patient, age of the family caregivers and gender of the patient.

This study had a number of strengths. There are barely any Indian studies that have looked at predictors of caregiver burden in first admission acute patients of schizophrenia. This study opens up to wider aspects of mental illnesses where caregivers may also face enormous challenge every day. We need to address the caregivers to help them in the continuum of care. Secondly, even though the study used cross sectional designs, the validated standardized tools were used in this study to establish severity of caregiver’s distress and to assess disability and burden.

However, the study was not without limitations. The study was a cross sectional study; thus, the observed association could not be interpreted as causal inferences.
The study was a single centred with small sample size. Hence the study findings could not be generalized to the rest of the population. Purposive sampling technique was employed for the study which is not a true representation of the general population. And self-reported measures often involve response bias or social desirability bias.

Conclusions

Majority of the caregivers in the study were females, with minimal educational qualification and were the spouse of the patients, with parents and siblings involved in care in a minor proportion of the patients. The mean duration of caregiving was 7 ± 5.87 years and mean time of caregiving as 7.63 ± 2.37 hours per day. In the study, the prevalence of psychological distress was 37.50%. 22(55%) reported moderate burden and 18(45%) reported severe burden. High distress and burden were reported in our study. The most important predictive factor of psychological distress in caregivers was the severity caregiving burden. However, a further longitudinal study may provide a better insight on burden and distress among caregivers of schizophrenia.

Conflict of interest

Nil.

References

1. Chang HY, Chiou CJ, Chen NS. Impact of mental health and caregiver burden on family caregivers’ physical health. Arch Gerontol Geriatr 2010;50(3):267-71.
2. Parabiahi A, Lasalvia A, Bonetto C, Cristofalo D, Marrella G, Tansella M, et al. Predictors of changes in caregiving burden in people with schizophrenia: a 3-year follow-up study in a community mental health service. Acta Psychiatr Scand Suppl 2007(437):66-76.
3. Reine G, Lancon C, Simeoni MC, Duplan S, Auquier P. Caregiver burden in relatives of persons with schizophrenia: an overview of measure instruments. Encephale. 2003;29(2):137-47.
4. Bury L, Zaborowski B, Konieczynska Z, Jarema M, Cikowska G, Kunicka A, et al. Family burden of schizophrenic patients with various forms of psychiatric care. Psychiatr Pol 1998;32(3):275-85.
5. Chien WT, Chan SW, Morrissey J. The perceived burden among Chinese family caregivers of people with schizophrenia. J Clin Nurs 2007;16(6):1151-61.
6. Durmaz H, Okanli A. Investigation of the effect of self-efficacy levels of caregiver family members of the individuals with schizophrenia on burden of care. Arch Psychiatr Nurs 2014;28(4):290-4.
7. Hanzawa S, Bae JK, Bae YJ, Chae MH, Tanaka H, Nakane H, et al. Psychological impact on caregivers traumatized by the violent behavior of a family member with schizophrenia. Asian J Psychiatr 2013;6(1):46-51.
8. Hou SY, Ke CL, Su YC, Lung FW, Huang CJ. Exploring the burden of the primary family caregivers of schizophrenia patients in Taiwan. Psychiatry Clin Neurosci 2008;62(5):508-14.
9. Hsiao CY, Tsai YF. Factors of caregiver burden and family functioning among Taiwanese family caregivers living with schizophrenia. J Clin Nurs 2015;24(11-12):1546-56.
10. Igerase OO, Morakinyo O, Lawani AO, James BO, Omoaregba JO. Burden of care among relatives of patients with schizophrenia in midwestern Nigeria. Int J Soc Psychiatry 2012;58(2):131-7.
11. Caqueo-Urizar A, Gutierrez-Maldonado J, Ferrer-Garcia M, Morales AU, Fernandez-Davila P. Typology of schizophrenic symptoms and quality of life in patients and their main caregivers in northern Chile. Int J Soc Psychiatry 2013;59(1):93-100.
12. Mantovani LM, Ferretjans R, Marcal IM, Oliveira AM, Guimaraes FC, Salgado JV. Family burden in schizophrenia: the influence of age of onset and negative symptoms. Trends Psychiatry Psychother 2016;38(2):96-9.
13. Provencher HL, Mueser KT. Positive and negative symptom behaviors and caregiver burden in the relatives of persons with schizophrenia. Schizophr Res 1997;26(1):71-80.
14. Ukpong D. Burden and psychological distress among Nigerian family caregivers of schizophrenic patients: the role of positive and negative symptoms. Turk Psikiyatri Derg 2012;23(1):40-5.
15. Jagannathan A, Thirthalli J, Hamza A, Nagendra HR, Gangadhar BN. Predictors of family caregiver burden in schizophrenia: Study from an in-patient tertiary care hospital in India. Asian J Psychiatr 2014;8:94-8.
16. Kumar CN, Suressa KK, Thirthalli J, Arunachala U, Gangadhar BN. Caregiver burden is associated with disability in schizophrenia: results of a study from a rural setting of south India. Int J Soc Psychiatry 2015;61(2):157-63.
17. Thara R, Padmavati R, Kumar S, Shriniwasan L. Burden assessment schedule instrument to assess burden on caregivers of chronic mentally ill. Indian J Psychiatr 1998;40(1):21-9.
18. Sartorius N, Janca A. Psychiatric assessment instruments developed by the World Health Organization. Soc Psychiatry Psychiatr Epidemiol 1996;31(2):55-69.
19. Kay SR, Fiszbein A, Opler LA. The positive and negative syndrome scale (PANSS) for schizophrenia. Schizophr Bull 1987;13:261-76.
20. Shah ST, Sultan SM, Faisal M, Irfan M. Psychological distress among caregivers of patients with schizophrenia. J Ayub Med Coll Abbottabad 2013;25(3-4):27-30.
21. Ong HC, Ibrahim N, Wahab S. Psychological distress, perceived stigma, and coping among caregivers of patients with schizophrenia. Psychol Res Behav Manag 2016;9:211-8.