

A Study of Caregiver Burden in Spouses of Patients with Schizophrenia

Prashanth Challuri¹, Bandela Sowmya Grace²

ABSTRACT

Introduction: Schizophrenia is a severe mental illness, resulting in impairing and debilitating worldwide. The primary care giver is expected to meet all the deficiencies of the sick relative leading to caregiver burden. So the present study aims to study the burden and factors influencing them, so as to decrease the burden, facilitate better prognosis. Current research aimed to study the caregiver burden in the spouses of patients with schizophrenia with the objectives to study the caregiver burden in the spouses of patients with schizophrenia and to study the factors influencing the caregiver burden.

Material and methods: A consecutive sample of spouses of 100 patients with schizophrenia were taken at IMH, Hyderabad. A semi structured questionnaire was administered to collect the socio demographic details. Followed by IDEAS for measuring and quantifying the mental illness, later BAS (burden assessment scale), to assess the burden. Statistical analysis was done using SPSS.

Results: The mean total burden is 82.68, majority were having moderate burden (76%). Severe burden was seen in undifferentiated schizophrenic patients, those with longer duration of illness (>10 years) and with severe disability, which were statistically significant ($p < 0.001$). More burden was seen with female gender, self employed spouses, financial dependence on patient. Mental illness in the spouse and having abused by the patient were found to be statistically significant.

Conclusion: Majority of the spouses experienced moderate level of burden. Factors like type of schizophrenia, duration of illness and severity of illness are significantly associated with level of burden. Psycho-therapeutic techniques like psycho education, family and couple therapy may help in better coping of spouses of mentally ill persons, to reduce burden.

Keywords: Schizophrenia, Spouses, Caregiver Burden.

INTRODUCTION

Schizophrenia is a severe mental illness, resulting in impairing and debilitating worldwide. The Global Burden of Diseases Report¹ revealed that schizophrenia mainly contributed to the disability around the world. The disability of the patients has disturbed the capabilities of people with mental illness and in turn could have an effect on their families. Long gone is the era of treating mentally in the asylums. The role of caregivers has gained a greater role, as a result of deinstitutionalization and increasing shift of psychiatric care to the community.² In today's world, psychiatric patients receive relatively short inpatient care and early discharge from the hospital, which adds to the important role of a caregiver.

Studies in India, show the majority of the people with schizophrenia stay with their families.³ On one hand, this development has led to immense progress for the patient because any hospital service cannot replace family

environment, but on the other hand caregivers face immense physical, social, emotional, and financial burden.²

A caregiver has been defined as a family member who has been living with the patient and has been closely involved in his/her activities of daily living, health care, and social interaction for more than a year.⁴ Burden of care is defined as “the presence of problems, difficulties or adverse events which affect the life of the psychiatric patients’ or significant others”.

Usually, relatives of patients with major psychiatric disorders feel burdened, as these disorders are Care giving, involves compromise of personal freedom, sacrifice of leisure time activities, financial difficulties, turbulence of relationships, lack of social support, coping with frustration, feeling of helplessness, loneliness, weakness and so on. Patients unpredictable behavior, inability to perform self care, closer kinship, higher number of psychotic episodes in previous year adds to the crises. These difficulties faced by a care giver in the process of care giving are collectively termed “family burden” or “care givers burden”² which is unpredictable and long lasting.

The way caregiver's handle the burden of care and their reactions to the aberrant behavior of the sick, differs from family to family. The psychological distress perceived by the caregiver is multifactorial depending upon his/her personality, severity of symptoms, extent of social support, financial resources etc.⁵ In the midst of care giving burden, most of the caregivers suffer from poor psychological health and the same progresses to develop mental illness and have higher rates of depression than the general population.⁶ Caregivers had a 63% higher risk of mortality than no caregivers.⁷ The prevalence of subjective psychological distress has also been found to be very high, with 29 to 60% of the caregivers judged to be suffering from diagnosable psychiatric disorders across different studies which have used the General Health Questionnaire or similar criteria. (Avasthi A 2010).⁸

Research evidence from different countries on family

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caregivers of persons with Schizophrenia generally support that there is inadequate help and support to the family caregivers (Chan et al 2009).⁹ Many family caregivers reported not having the knowledge and skills necessary to take on the responsibilities of care giving for these relatives. Thus, they are unable to cope with a considerable amount of the caring roles and responsibilities (Chan et al 2009).⁹

Studies from India have shown that the burden of care of Schizophrenia is either similar to or even more than chronic physical illnesses. The amount of burden in Schizophrenia has more effect on family than the financial burden. By now the huge burden associated with caring for a family member with psychotic condition is well established.^{10,11} So the present study aims to study the burden and factors influencing the burden in the spouses of patients with schizophrenia, to decrease the burden, so as to facilitate better prognosis and to improve the quality of life.

Aim: To study the caregiver burden in the spouses of patients with schizophrenia.

Objectives

1. To study the caregiver burden in the spouses of patients with schizophrenia.
2. To study the factors influencing the caregiver burden.

MATERIAL AND METHODS

Study design: A cross sectional study conducted at Institute of mental health, Hyderabad. This is a tertiary psychiatric center, which is 800 bedded psychiatric hospital. A consecutive sample of spouses of 100 patients with schizophrenia (according to ICD – 10 criteria), who are both inpatients and outpatients in the family wards were selected. Inclusion and exclusion criteria were assessed. Informed consent in writing was obtained before patients were included in the study. On first contact with the study subjects, a semi structured questionnaire was administered to both patient and his/her spouse to collect the socio demographic details. This was followed by a detailed physical examination to assess the presence of coexisting physical complications. Positive findings and deficits were recorded. IDEAS (Indian disability and evaluation scale) was administered to the

patient for measuring and quantifying the mental illness, followed by administering, BAS (burden assessment scale) to the spouse of the patient to assess the burden, factors influencing the burden.

Inclusion criteria

1. Spouses of schizophrenia patients, who were diagnosed as per ICD-10.
2. Who has given written informed consent.
3. 18-60 years of age, either gender.
4. Patients with schizophrenia more than 2 years.
5. Spouses who are living with the patient over a period of 2 years.

Exclusion criteria

1. Patients with mental retardation, organic brain disease, major medical illness like HTN, DM, etc.
2. Who did not give the consent.
3. Spouses who had mental retardation, major medical illness like HTN, DM, etc.

STATISTICAL ANALYSIS

Statistical analysis was done using statistical package for the social sciences (spss) for windows version 19. Quantitative data is analyzed using percentages and bar graphs; Qualitative data is analyzed using chi-squared test. p value <0.05 was considered significant.

RESULTS

Sociodemographic characteristics of the spouses:

Out of 100 spouses, 65% were females and 35% were males, 13% were illiterates, 35% had studied up to elementary, 35% upto high school standard, where as graduate and post graduate were only 3% each.

In employment status, we found that 9% were employed for full time, 21% were employed for part time, 29% were self employed, 19% were un employed and only 8% were homemakers. Majority of them were self employed in the current study in order to meet the expenses. Most of the spouses had made monthly income in between Rs 2500 - Rs 5000 (37%) followed by 33%, with a monthly income > Rs 10,000 and 26% of them had a monthly income between Rs 5000 - Rs 10,000. Only 4% of them earned below Rs 2500

| | Mean | Standard deviation | Minimum | Maximum | Median |
|--------------|-------|--------------------|---------|---------|--------|
| Total burden | 82.68 | 11.24 | 56 | 106 | 86 |

Table-1: Total burden in spouses of schizophrenic patients

| Domains | Mean | Median | Minimum | Maximum | Standard deviation |
|----------------------------|------|--------|---------|---------|--------------------|
| Support of the patient | 16.3 | 16 | 13 | 20 | 2.1 |
| Care givers routine | 14.5 | 14 | 9 | 19 | 2.7 |
| External support | 14.2 | 14 | 10 | 18 | 2.2 |
| Spouse related | 5.3 | 4.5 | 1 | 12 | 3.5 |
| Patients behavior | 18.3 | 18 | 13 | 24 | 2.7 |
| Physical and mental health | 19.2 | 19.5 | 11 | 27 | 3.4 |
| Other relations | 11.0 | 11 | 7 | 14 | 1.4 |
| Taking responsibility | 9.1 | 9 | 6 | 12 | 1.5 |
| Care givers strategy | 10.8 | 11 | 7 | 15 | 2.0 |

Table-2: Burden scores in 9 domains

| | Burden | | | |
|--|--------|-----|--------------------|--------------------------|
| | Mean | N | Standard deviation | Sig |
| 1) Age of spouse | | | | |
| 15-30 years | 77.5 | 24 | 13.0 | p= 0.33 r=0.20 |
| 30-45 years | 84.3 | 45 | 9.3 | |
| >45 years | 84.2 | 31 | 11.4 | |
| Total | 82.6 | 100 | 11.2 | |
| 2) education of the spouse | | | | |
| Illiterate | 84.3 | 13 | 11.6 | p = 0.52 r = - 0.06 |
| Elementary | 82.6 | 35 | 10.3 | |
| High school | 82.3 | 35 | 12.3 | |
| Pre university | 80.0 | 11 | 12.4 | |
| Graduate | 79.3 | 3 | 5.6 | |
| Post graduate | 75.0 | 3 | 8.1 | |
| Total | 82.6 | 100 | 11.2 | |
| 3) sex of the spouse | | | | |
| Male | 79.34 | 35 | 11.9 | p= 0.029* |
| Female | 84.47 | 65 | 10.4 | |
| Total | 82.68 | 100 | 11.2 | |
| 4) Domicile | | | | |
| Urban | 79.55 | 29 | 11.06 | p = 0.075 |
| Rural | 83.95 | 71 | 11.13 | |
| Total | 82.68 | 100 | 11.24 | |
| 5) Family type | | | | |
| Nuclear | 83.32 | 71 | 10.99 | P = 0.373 |
| Extended | 81.10 | 29 | 11.86 | |
| Total | 82.68 | 100 | 11.24 | |
| 6) Employment status of the spouse | | | | |
| Employed full time | 82.0 | 9 | 11.1 | p = 0.026* r = -0.051 |
| Employed part time | 80.8 | 21 | 11.0 | |
| Self employed | 85.9 | 29 | 11.2 | |
| Unemployed | 81.7 | 19 | 11.3 | |
| Retired | 83.7 | 14 | 10.0 | |
| Home maker | 76.7 | 8 | 12.9 | |
| Total | 82.6 | 100 | 11.2 | |
| 7) Financial dependence on the patient | | | | |
| Yes | 81.8 | 45 | 12.7 | p = 0.04* r = 0.07 |
| No | 83.4 | 55 | 9.8 | |
| Total | 82.6 | 100 | 11.2 | |
| 8) Monthly income of the spouse | | | | |
| <Rs1000 | 85.9 | 1 | 0 | p = 0.056 r=-0.07 |
| Rs 1000-2500 | 84.1 | 3 | 7.2 | |
| Rs 2500-5000 | 79.5 | 37 | 11.6 | |
| Rs 5000-10,000 | 78.0 | 26 | 9.6 | |
| > Rs 10,000 | 72.3 | 33 | 11.4 | |
| Total | 82.6 | 100 | 11.24 | |
| 9) mental illness in the spouse | | | | |
| Yes | 86.2 | 15 | 12.0 | p = 0.018* |
| No | 82.0 | 85 | 11.0 | |
| Total | 82.6 | 100 | 11.2 | |
| 10) H/O substance abuse in the spouse | | | | |
| Yes | 83.1 | 16 | 13.2 | p = 0.86 |
| No | 82.5 | 84 | 10.9 | |
| Total | 82.6 | 100 | 11.2 | |
| 11) H/O abuse in the spouse | | | | |
| Yes | 100.8 | 6 | 4.4 | p = 0.001* |
| No | 81.5 | 94 | 10.5 | |
| Total | 82.6 | 100 | 11.2 | |

Table-3: comparison of mean burden with the spouse details

| Type of schizophrenia | Burden | | | P value |
|-------------------------|--------|----------|--------|-------------|
| | Mild | Moderate | Severe | |
| Paranoid | 8 | 40 | 0 | p = 0.001 * |
| Undifferentiated | 0 | 15 | 7 | |
| Hebephrenic | 0 | 4 | 0 | |
| Not otherwise specified | 8 | 15 | 1 | |
| ATPD | 0 | 2 | 0 | |
| Total | 16 | 76 | 8 | |

Table-4: Comparison of severity of burden with diagnosis of patient

| Duration of illness | Burden | | | P value |
|---------------------|--------|----------|--------|---------|
| | Mild | Moderate | Severe | |
| < 2 years | 12 | 2 | 0 | 0.001 * |
| 2-5 years | 4 | 30 | 0 | |
| 5-10 years | 0 | 40 | 2 | |
| > 10 years | 0 | 4 | 6 | |
| Total | 16 | 76 | 8 | |

Table-5: Comparison severity of burden with duration of illness

| Severity of illness | Burden | | | P value |
|---------------------|--------|----------|--------|---------|
| | Mild | Moderate | Severe | |
| No disability | 12 | 0 | 0 | 0.001 * |
| Mild | 4 | 40 | 0 | |
| Moderate | 0 | 25 | 1 | |
| Severe | 0 | 11 | 7 | |
| Profound | 0 | 0 | 0 | |
| Total | 16 | 76 | 8 | |

Table-6: Comparison severity of burden with the severity of illness

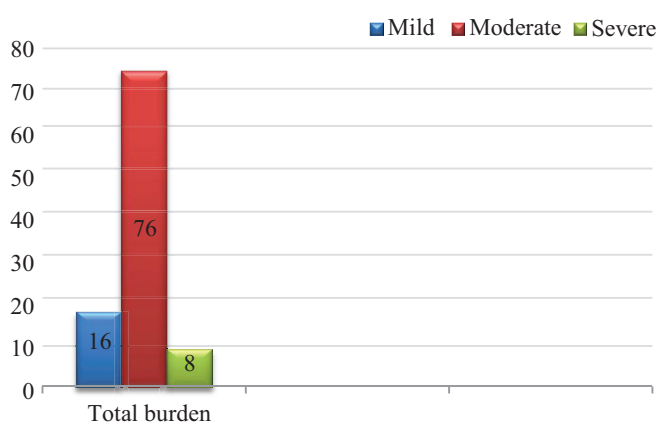


Figure-1: Burden distribution among spouses

per month. Financial dependence on patients were seen in 45% of the spouses. Remaining 55% had made their own ways to earn monthly income. In the above study 85% of the spouses did not had any mental illness. 84% of the spouses had no history of substance abuse. Abuse in the spouses was not seen in 95%, where as 5% of them suffered with abuse by patients with schizophrenia.

Caregiver burden in the spouses

Table 1 shows that the mean burden among spouses of schizophrenia patients was 82.68 ± 11.24

Table 2, shows the mean burden scores of nine domains are, Support of the patient - 16.3, Care givers routine - 14.5, External support - 14.2, Spouse related - 5.3, Patients behavior

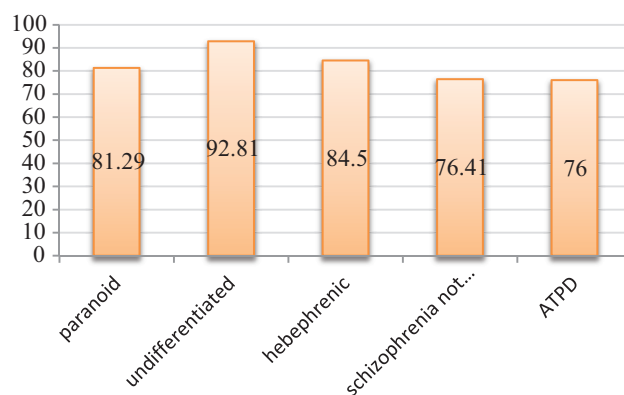


Figure-2: Comparison of mean spousal burden with the diagnosis

- 18.3, Physical and mental health - 19.2, Other relations - 11.0, Taking responsibility - 9.1, Care givers strategy - 10.8. highest mean burden score was seen in physical and mental health domain followed by patients behavior, caregivers routine and external support. Least mean burden is seen in spouse related.

Table 3, shows the comparison of mean burden with the details of the spouse, of which gender, employment, financial dependence on patient, mental illness in the spouse, spouses who faced abuse had suffered with more burden, which was statistically significant with the p value $< 0.05^*$.

Fig 2, shows the mean burden was more in undifferentiated schizophrenia (92.81 ± 8.4) followed by hebephrenic (84.50 ± 9.8), which was found to be statistically significant. (p value = 0.001).

Mild burden was seen in 16% of the spouses of the patients, with equal distribution between paranoid schizophrenia and schizophrenia not otherwise specified. Moderate burden was seen in 76% of the spouses, in which majority of the patients were found to be suffering with paranoid schizophrenia. Severe burden was seen in 8% of the spouses, mainly in the spouses of the undifferentiated schizophrenia patients, which was found to be statistically significant (p value = 0.001) (Table 4).

Mild burden was seen with lesser duration of illness, i.e. < 2 years, moderate burden was seen with 5 - 10 years of duration of illness, severe burden was seen in patients having illness for > 10 years, which was statistically significant. (p = 0.001*) (Table 5)

Table 6 shows, majority of the spouses who faced mild burden had no disability (N= 12/16; 75%). Spouses who faced moderate burden had mild disability (40/76; 52.6%), moderate disability (25/76; 32.8%) and severe disability (11/76; 14.4%). Spouses who had severe burden, majority of them had severe disability (7/8; 87.5%), which was found to be statistically significant with p value 0.001*

DISCUSSION

Majority of the spouses were females, who were illiterates and some had studied up to elementary level. Most of them were self employed with a monthly income between Rs 2500 - 5000 per month and only 45% of the spouses were financially dependent on the patients. Of the 100 spouses 15% of them had suffered with mental illness, 16% of them had substance abuse and only 5% had suffered abuse by the patients. The demographic details and other characteristic findings in the above study was in accordance with previous studies like Anupama Rammohan et al.¹²

The mean total burden was 82.68. Up on categorizing the severity of burden distribution in to mild (40 - 70); moderate (70 - 100) and severe (101 - 120); majority (76%) of them had moderate burden as shown in table 1 and fig 1. Which was in accordance with study done by Aditya G, RK Solanki et al in 2015 on burden in caregivers of patients with schizophrenia.¹³

Burden was distributed among nine domains in spouses of the schizophrenia patients, of which highest mean burden score was seen in physical and mental health domain followed by patients behavior, caregivers routine and external support. Least mean burden was seen in spouse related as shown in table 2. The role of patient's disturbed behavior in increasing care giver burden and consequences of intense care giving on care giver's health were reported in the earlier studies¹⁴

Mean burden in the male spouses (n= 35) is 79.34±11.9 and that of the female spouses (n=65) is 84.47±10.4. This shows that female spouses had more burden than the males with a p value of 0.029 *, which was statistically significant. In study done by S Kumar, S Mohanty et al, on spousal burden of care in schizophrenia. The gender effects were evident on total burden and in following areas—external support, caregivers routine, support of patient, patients behavior and caregivers strategy. Females experienced greater burden. The result is

in expected direction.

On comparison of mean burden with the employment status of the spouses, higher burden was seen in those who are self employed followed by retired persons, which was statistically significant with a p value of 0.026*. As the spouse monthly income increased, burden suffered by them was reduced with a negative correlation of r = -0.07. In a study conducted by Choudhary R et al (1992-93) in an urban teaching centre compared the caregivers burden in schizophrenia and bipolar disorder (BPD). Young, low income unemployed males reported higher burden.¹⁵

Spouses who were financially dependent on the patients for their expenses had faced less burden when compared to those who were not dependent on them, which was statistically significant with a p value - *96. of 0.04*. In a study done by Esra Y and Umit K et al found that as the patient's monthly income decreased, caregiver burden increased. A fair income for the patient are important factors in decreasing caregiver burden.¹⁶ The data on low income levels show that governments should review their policies for supporting caregivers.

The spouses who suffered with mental illness had a higher mean burden (86.2±12.0), than in those who had no mental illness (82.0±11.0). This shows that spouses who had higher burden are suffered with mental illness, which was statistically significant with a p value of 0.018*. A study in Ontario, Canada on mental health in informal caregivers showed a significantly higher prevalence of mental disorders than the general population.

Burden was higher in the spouses who faced abuse by the patients, which was statistically significant with a p = 0.001*. In a study done by H. Ahlem, Y. Zgueb et al. on family burden in caregivers of schizophrenia found that Levels of burden were significantly associated with history of aggressive acting out by the patients on their spouses (p < 0.005). This was similar to the finding in our study.¹⁷

As patients with paranoid schizophrenia had no greater personality deterioration and are presented with positive symptoms, which had good response to the medication and this type of schizophrenia had good prognosis than others, that might be the reason for the spouses of patients suffering with this diagnosis had mild to moderate burden only and none of them are had severe burden as shown in table 4. In contrast to our findings, the positive symptoms raised the burden on relatives was supported by a study conducted in Hong Kong (2007).¹⁸ Undifferentiated schizophrenia patients presents with mixture of symptoms of all types and it is comparatively had a poor prognosis and respond less to pharmacotherapy. Majority of spouses of this kind of schizophrenia patients suffered with moderate to severe burden. Whereas acute and transient psychotic disorder had shorter duration of course, responding well to medication had mild burden compared to other types.

As the duration of illness in patients increased the spousal burden also increased with a positive correlation (r = 0.8), which was statistically significant with the p value - 0.001* as shown in table 5. In a study done by Aarti J et al, on Predictors

of family caregiver burden in schizophrenia: Study from an in-patient tertiary care hospital in India, found duration of illness and levels of psychopathology and disability had significant direct correlation with total burden score.¹⁹ In the same manner Kar et al also reported that duration of illness had statistically significant impact on care giving burden.²⁰

In the current study as the severity of illness increased the mean burden value also increased, showed a positive correlation value of $r = 0.85$, which was found to be statically significant with a p value = 0.001 as shown in table 6. The above findings are in accordance with the study done by Ochoa S et al, showed, that severity of psychotic symptoms and disability are related to higher levels of family burden.²¹

Limitations

1. The current study was conducted at a tertiary care center that may not represent the general population.
2. Study population was mostly from the lower socioeconomic group. So the results cannot be generalized for middle and higher economic groups.
3. This is a hospital based cross sectional study on a small group of patients.
4. Other factors that influence experience and reporting of burden like social support and expressed emotions were not taken into account.
5. This is a cross sectional study and more prospective studies are needed in further understanding of the burden in spouses of mentally ill person

CONCLUSION

The study aimed to look at the burden in the spouses of patients with schizophrenia. Majority of the spouses experienced moderate level of burden. Certain factors like type of schizophrenia, duration of illness and severity of illness are significantly associated with level of burden. Mean burden was compared with socio demographic details of the spouses, we found that the mean burden was more in elderly age group, illiterates, female gender, rural background, nuclear type of family, self employed, who are financially not dependent on the patient, with a monthly income < Rs 1000, spouses who are having mental illness, having substance abuse and faced abuse by the patient. Of which factors like female gender, self employed spouses, financial dependence on patient, mental illness in the spouse and having abused by the patient are found to be statistically significant.

Future directions

- In view of perceived burden in the spouses of mentally ill persons, need to develop family intervention programs focusing on psycho education to family members and imparting skills to manage spouses is present.
- Access to better rehabilitation and psycho social services to be ensured to patients.
- Self help groups for spouses should be encouraged where they can seek mutual support, learn from others' experiences and share problems with others to better cope with spouse illness.

- Periodic screening of spouses is required given their vulnerability to develop psychological problems.
- Financial incentives from the government agencies can help in reducing the burden of spouse

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