

## Spousal Caregiver Burden and Its Relation with Disability in Schizophrenia

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### ABSTRACT

**Background:** Schizophrenia, a chronic psychiatric disorder, can affect one's productivity and psychosocial functioning. In Indian context, the responsibility of caring persons with schizophrenia is increasingly on their spouses. Spousal caregiver experience and its relation with disability in schizophrenia need to be studied. **Materials and Methods:** We conducted a cross-sectional study among 52 outpatients with schizophrenia and their spouses attending a tertiary psychiatric center. The objectives were: (a) to explore spousal caregiver burden in schizophrenia and (b) to assess the relation between disability and spousal caregiver burden. The study adopted recommended ethical principles. Scales such as Burden Assessment Schedule, Indian Disability Evaluation and Assessment Scale (IDEAS), and Positive and Negative Syndrome Scale were used to collect appropriate data. Descriptive analysis, bivariate analysis, and multivariate analysis were done in SPSS software version 16.0. **Results:** The mean spousal caregiver burden score was 73.5 (standard deviation: 14.0). In bivariate analysis, disability, duration of schizophrenia, severity of schizophrenia, place of residence, and socioeconomic status had statistically significant relation with spousal caregiver burden. Adjusted for spouses' age, gender, and other significant factors in bivariate analysis, the IDEAS global disability score (2.6, [confidence interval 0.5–3.8,  $P = 0.013$ ]) retained statistically significant association with spousal caregiver burden. **Conclusion:** Spouses of persons with schizophrenia experience significant caregiver burden. Disability was found to be the most powerful determinant of spousal caregiver burden in the sample. Focus on disability alleviation in the management of schizophrenia may help reduce spousal caregiver burden.

**Key words:** Disability, schizophrenia, spousal caregiver burden

### INTRODUCTION


The psychological, physical, and financial cost of providing long-term care for persons suffering from schizophrenia has been well documented.<sup>[1]</sup> Especially

when access to health services is limited, this disease, manifesting in the prime of adulthood and running a chronic and sometimes progressive course, wreaks havoc with productivity and psychosocial functioning.

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The provision of a supportive, noncritical environment would be second in importance only to timely and titrated pharmacological intervention.

The burden of care falls on the family, especially where psychiatric or rehabilitative services are in short supply. As India shifts from joint or extended family setup to nuclear families, the spouse takes on the caregiving that was previously shared by parents and siblings.<sup>[2,3]</sup>

The challenges that prevail when the spouse is the primary caregiver differ from the experience of or expectations from, other possible caregivers. A drop in income, lack of intimacy or reciprocity within the marital relationship, and an increase in parenting responsibilities are all challenges particular to the spouse who is the primary caregiver.

There is a paucity of studies on the specific issue of spousal caregiving burden in schizophrenia.<sup>[4-24]</sup> Among the studies which have focused on spousal caregiver burden<sup>[4-42]</sup> and within the constraints of limited sample size, gender,<sup>[32,38,39]</sup> age of spouse,<sup>[32,36,38]</sup> duration of marriage,<sup>[36,38]</sup> number of children,<sup>[38]</sup> place of residence,<sup>[35,36]</sup> and family type<sup>[32,36]</sup> were found not to be associated with the degree of burden. While the spouses' monthly income did not predict spousal caregiver burden,<sup>[38]</sup> spouses involved in gainful employment reported less burden.<sup>[36]</sup> The spouses' years of schooling were largely unrelated to burden<sup>[32,36]</sup> except for one study which suggested a negative correlation.<sup>[38]</sup>

Studies on the effect of illness characteristics on spousal burden have shown that, while duration of illness does not influence burden,<sup>[35]</sup> psychosocial dysfunction does.<sup>[37]</sup> Kumar *et al.* reported that psychosocial dysfunction in social, vocational, family, cognitive, and personal areas had medium effect on spousal burden.<sup>[37]</sup>

Among the variables known to influence spousal burden, the deficits in functioning caused by schizophrenia under the category of disability seem to be one that may be modifiable by treatment strategies. Impairment of self-care and independent living skills, of communication and affectivity as well as the ability to earn money, can understandably multiply caregiver burden. More importantly, modifying disability through pharmacological and psychological intervention may be an important and feasible method of reducing caregiver burden.

In summary, there is a good reason to believe that the spouse often plays a central role in providing care that is crucial to the survival and well-being of the person suffering from schizophrenia. It is, therefore, important to be able to understand the unique vulnerabilities

and the determining variables that prevail within this relationship. This study was conducted to elucidate the relationship between spousal caregiver burden and disability consequent to schizophrenia.

## MATERIALS AND METHODS

### Study setting and study population

The study was conducted at the department of psychiatry of a tertiary care center from South India using available extensive medical records. Participants were recruited from among those attending the review outpatient clinic.

Study population included patients with schizophrenia (diagnosed by the International Classification of Diseases 10) and their spouses. The inclusion criteria for patients were: minimum age of 18 years, married, Tamil speaking, minimum duration of illness of 1 year, stable course for 6 months prior to study recruitment (as evidenced by the absence of inpatient care during the previous 6 months and by the absence of changes in medication for symptom control during the previous 6 months), and absence of comorbid psychiatric illness or intellectual disability. The inclusion criteria for spouses were: minimum age of 18 years, Tamil speaking, without previously diagnosed psychiatric illness, and fulfilling the role of primary caregiver for previous 6 months. A primary caregiver was defined as one who lived with the person with schizophrenia and provided care in areas such as activities of daily living, treatment, and drug supervision, as required.

### Instruments

#### *Burden Assessment Scale*<sup>[43]</sup>

The Burden Assessment Scale (BAS), developed by Schizophrenia Research Foundation, is designed to assess caregiver burden among primary caregivers of chronic mentally ill persons. This tool was originally validated in Tamil-speaking caregivers of persons with schizophrenia, matching the language and disease characteristics of this study.

The tool assesses both objective and subjective domains of caregiver burden. Forty items are grouped under the following factors, namely, spouse related (identifies burden on spousal relation), physical and mental health (identifies burden on caregivers' physical health and mental health due to caregiving), external support (identifies burden due to limited support from external sources), caregivers' routines (explores how far caregiver routine is affected due to caregiving role), support of patients (identifies burden attributed to need to support the patient), taking responsibility (identifies burden attributed to taking up greater responsibility), other relations (identifies

how far caregiver relationships are affected due to caregiving role), patients' behavior (identifies burden attributed to patients' maladaptive behavior), and caregivers' strategy (identifies strategies adopted by caregiver as part of caregiving). The psychometric properties of BAS include fair inter-rater reliability ( $\kappa = 0.80$ ) and fair criterion validity with Family Burden Schedule<sup>[44]</sup> (correlation ranging between 0.71 and 0.82).

Scoring: Each item is rated from 1 to 3. The minimum score is 40 and maximum score is 120 with higher scores indicating greater burden.

#### *Indian Disability Evaluation and Assessment Scale<sup>[45]</sup>*

The Indian Disability Evaluation and Assessment Scale (IDEAS) is a 4-item scale to assess disability in mental illness. It was developed by Rehabilitation Committee of Indian Psychiatric Society in 2002. The "IDEAS" is gazetted by the Ministry of Social Justice and Empowerment, Government of India, as a tool to assess and quantify disability in mental illness. The items include self-care, interpersonal activities, communication and understanding, and work. The IDEAS provide additional weightage for duration of illness. The rating follows information obtained from all possible sources.

Scoring: Each item is rated from 0 to 4. Global Disability Scale score is calculated by adding the total score and duration of illness score; the global disability score ranges from 0 to 20. Based on global disability score, degree of disability can be categorized as follows: score 0 = no disability, score 1–6 = mild disability, score 7–13 moderate disability, score 14–19 = severe disability, and score 20 = profound disability.

#### *Positive and Negative Syndrome Scale<sup>[46,47]</sup>*

The Positive and Negative Syndrome Scale (PANSS) is a 30-item scale that assesses positive symptoms, negative symptoms, general psychopathology, and their relation to each other. The items were adapted from the Brief Psychiatric Rating Scale and Psychopathology Rating Schedule. The scale has good inter-rater reliability and criterion validity. The rating is based on previous 1 weeks' report from family member and on 30–40 min semi-formalized psychiatric interview.

Scoring: There are 7 items each in positive scale and negative scale and 16 items in General Psychopathology Scale. Each item is rated on a severity scale from 1 to 7. For positive scale and negative scale, the total score ranges from 7 to 49 and the score for General Psychopathology Scale ranges from 16 to 112. Higher score denotes greater severity on each scale.

#### *Other instruments*

A self-devised questionnaire was used to collect sociodemographic details and illness details. Kuppuswamy's Socioeconomic Status Scale update for income was used to assess socioeconomic status.<sup>[48]</sup>

#### **Procedure**

The study was approved by the Institutional Ethics Committee of Christian Medical College, Vellore. The study was cross-sectional in design. The participants (patients and spouses) satisfying selection criteria were recruited consecutively from the review outpatient clinic. Of the 52 participants, none denied consent, possibly because the interview followed the routine review examination and did not entail additional visits or interventions. After obtaining informed written consent, the first author administered BAS to the spouse; followed by PANSS rating. The second author collected details regarding sociodemographic profile and administered IDEAS.

#### **Statistical analysis**

Continuous study variables were summarized using means and standard deviations (SDs) and categorical variables with frequencies and percentages. Relationship between spousal caregiver burden score and IDEAS global disability score was assessed using Pearson's correlation coefficient. The association between spousal caregiver burden and sociodemographic variables was assessed using independent two-sample *t*-test. Relationships between spousal caregiver burden score and schizophrenia-related variables were assessed using Spearman's correlation coefficient. Variables with  $P < 0.05$  in the bivariate analysis were considered in multivariable linear regression analysis to identify relation between spousal caregiver burden and disability. All analyses were done using SPSS software version 16.0 (SPSS Inc., Chicago).

## **RESULTS**

### **Sociodemographic details of patients and their spouses**

Of the 52 couples (patients and respective spouses), 30 spouses (57.7%) were men and 22 spouses were women. The mean age of spouses was 42.4 years (SD: 11.1) (men: 46.6 years [SD: 10.6]; women: 36.6 years [SD: 9.3]). The mean age of patients was 40.0 years (SD: 10.2) (women: 38.8 years [SD: 10.6], men: 41.7 years [SD: 9.7]). Further, sociodemographic details of spouses are mentioned in Table 1.

The majority of the families were from lower socioeconomic, rural, Hindu background, and lived as nuclear families. On regrouping socioeconomic status as lower (combining lower lower and upper lower) and

middle and above (combining lower middle, upper middle, and upper), 32 spouses (64%) were from lower socioeconomic background and 18 spouses (36%) were from middle and above socioeconomic background.

### Clinical profile of patients with schizophrenia [Table 2]

The duration of schizophrenia ranged from 1 year, 4 months to 30 years, 1 month, with mean duration of 112.2 months (SD: 70.9). Based on the IDEAS global disability score, 31 patients (60.8%) had mild disability and 20 (39.2%) had moderate disability. No patient was free of disability or scored in the range of severe or profound disability. Five patients (9.6%) reported a history of substance use.

**Table 1: Psychosocial profile of spouses of patients with schizophrenia**

Variable (sample size, n)	Frequency (%)
Religion (n=52)	
Hindu	42 (80.8)
Christian	6 (11.5)
Muslim	4 (7.7)
Type of family (n=51)	
Joint	14 (27.5)
Nuclear	37 (72.5)
Place of residence (n=52)	
Rural	29 (55.8)
Urban	23 (44.2)
Additional caregiving role (n=52)	
Present	5 (9.6)
Absent	47 (90.4)
Socioeconomic status (n=51)	
Lower lower	2 (4.0)
Upper lower	30 (60.0)
Lower middle	9 (18.0)
Upper middle	8 (16.0)
Upper	1 (2.0)
Employment status of spouse (n=44)	
Employed	35 (79.5)
Unemployed	9 (20.5)

**Table 2: Illness profile of patients with schizophrenia**

Variable (sample size, n)	Mean (SD)
Disability* (n=51)	
Self-care	0.5 (0.8)
Interpersonal activity	0.7 (0.7)
Communication and understanding	1.1 (0.9)
Work	1.3 (1.4)
Global Disability Scale score	5.3 (3.5)
Severity of schizophrenia† (n=51)	
Positive score	8.7 (3.2)
Negative score	15.1 (6.9)
General psychopathology	24.9 (6.0)

\*Disability assessed by IDEAS; †Severity of schizophrenia assessed by PANSS. IDEAS – Indian Disability Evaluation and Assessment Scale; PANSS – Positive and Negative Syndrome Scale; SD – Standard deviation

### Spousal caregiver burden

Spousal caregiver burden of 49 spouses, whose BAS scores were available, ranged from 50 to 99 with a mean score of 73.5 (SD: 14.0). For male spouses (28), the BAS score ranged from 50 to 99 and the mean score was 72.1 (SD: 14.5). For female spouses (21), the BAS score ranged from 52 to 96 and the mean score was 75.4 (SD: 13.4).

### Bivariate relation of spousal caregiver burden with disability and other factors

For further analysis, BAS score, the dependent variable denoting spousal caregiver burden, was retained as continuous variable. BAS score skewness was consistent with the data being normal (skewness coefficient 0.059, standard error 0.340). The IDEAS global disability score was retained as continuous variable. Other independent variables were grouped under demographic, clinical, and psychosocial variables.

#### Correlation of spousal caregiver burden with disability

There was a positive correlation between spousal caregiver burden score and IDEAS global disability score (Pearson's correlation coefficient,  $r = 0.588$ ). This positive correlation between spousal caregiver burden and disability was statistically significant ( $P < 0.001$ ).

#### Correlation of spousal caregiver burden with demographic variables

Neither age of patient (Pearson's correlation coefficient,  $r = 0.078$ ,  $P = 0.596$ ) nor age of spouse (Spearman's correlation coefficient,  $r_s = 0.038$ ,  $P = 0.796$ ) had statistically significant correlation with spousal burden. Though female spouses reported slightly higher burden than male spouses, the difference was not statistically significant (independent sample  $t$ -test,  $t = -0.800$ ,  $P = 0.428$ ).

#### Correlation of spousal caregiver burden with other clinical variables

Spousal caregiver burden had statistically significant positive correlation with duration of schizophrenia (Spearman's correlation coefficient,  $r_s = 0.751$ ,  $P = 0.040$ ) and PANSS General Psychopathology Score (Spearman's correlation coefficient,  $r_s = 0.38$ ,  $P = 0.007$ ). Spousal caregiver burden did not have statistically significant correlation with PANSS positive score (Spearman's correlation coefficient,  $r_s = 0.232$ ,  $P = 0.108$ ) or PANSS negative score (Spearman's correlation coefficient,  $r_s = 0.266$ ,  $P = 0.065$ ).

#### Association of spousal caregiver burden with psychosocial variables [Table 3]

Analysis of the independent categorical psychosocial variables such as type of family, place of residence, socioeconomic status, additional caregiving role, and

**Table 3: Association of spousal caregiver burden with psychosocial characteristics of spouses of patients with schizophrenia using independent sample t-test**

Independent variable	Mean caregiver burden (SD)	t (P)
Type of family		
Nuclear family	74.9 (14.0)	-1.074 (0.28)
Joint family	70.0 (14.4)	
Place of residence		
Rural	78.7 (13.3)	2.966 (0.005)*
Urban	67.7 (12.6)	
Additional caregiver role		
Present	78.2 (13.3)	-0.786 (0.43)
Absent	73.0 (14.1)	
Socioeconomic status		
Lower	78.3 (13.7)	2.875 (0.006)*
Middle and upper	67.1 (11.9)	
Employment status of spouse		
Employed	75.3 (14.8)	-1.321 (0.19)
Unemployed	67.9 (11.6)	

\*Statistically significant at  $P < 0.05$ . SD – Standard deviation

spouses' employment status revealed the following: spouses from rural areas reported significantly greater caregiver burden than those from urban area ( $P = 0.005$ ); spouses' mean BAS score from lower socioeconomic status was statistically significantly higher than mean BAS score from middle and upper socioeconomic status ( $P = 0.006$ ) and; type of family, spouses' additional caregiver role, and spouses' employment did not have any significant association with spousal caregiver burden.

### Multivariate relation of spousal caregiver burden with disability

To further understand the relation of spousal caregiver burden with disability, the factors that had statistically significant relation in bivariate analysis were included in linear regression analysis. Those factors such as global disability score, socioeconomic status, place of residence, duration of schizophrenia, PANSS General Psychopathology Score, and spouses' age and gender were also included in the model. Adjusted for those variables in the model, one unit increase in disability score predicted 2.6 unit increase in spousal caregiver burden (confidence interval 0.5–3.8,  $P = 0.013$ ). While place of residence still retained significant relation with spousal caregiver burden, variables such as socioeconomic status, duration of illness, and severity of illness lost significant relation. This regression model could explain 48% of variance in spousal caregiver burden.

## DISCUSSION

The focus of the study was on caregiver burden experienced by spouses of persons suffering from schizophrenia and the nature of the relationship between spousal caregiver burden and disability.

Significant levels of caregiver burden were elicited from 52 predominantly male, employed, middle-aged spouses, the majority of whom hailed from rural, Hindu, low socioeconomic, nuclear families. The high levels of burden reported are similar to that reported by Jagannathan *et al.* and Rammohan *et al.*<sup>[29,34]</sup>

Greater burden reported by female spouses, although not reaching statistical significance in this study, is in agreement with the findings by Kumar and Mohanty.<sup>[35]</sup> Possible reasons for this finding, if it holds true, could vary from greater ease among women in confiding the experience of burden/reporting burden or the addition of income generation to already existing roles of homemaker and parental responsibilities.

Neither the age of the spouse nor of the patient was associated with greater experience of burden. Unlike what was reported by Kumar *et al.*,<sup>[36]</sup> this study could not establish association between gainful employment of spouse and spousal burden.

Rural residence and low socioeconomic status were positively associated with the degree of caregiver burden, while type of family and additional roles incumbent on caregiver were not. While it is beyond the scope of this study to provide definite conclusions, given the cost and low accessibility of health care, especially in rural areas, the finding that greater burden is associated with rural rather than urban residence and with low socioeconomic background is understandable.

### Disability

Disability as measured by the IDEAS was strongly correlated with caregiver burden ( $P < 0.001$ ). This association is apparent even though only mild-to-moderate levels of disability were prevalent in this population. It is likely therefore that severe levels of disability would be more strongly correlated with caregiver burden.

### Severity of schizophrenia

The score of caregiver burden correlates with General Psychopathology Score on PANSS which is a measure of severity of illness. The study finding thus confirms that severity of illness in the patient predicts spousal burden. It may be justifiable to extrapolate that disability caused by illness mediates the influence of severity of illness on burden experienced by spouses.

### Duration of schizophrenia

Caregiver burden was associated with duration of schizophrenia ( $P = 0.040$ ) unmediated by the function of age since there was no association with age of either spouse or patient.

## CONCLUSION

Male spouses of persons suffering from chronic schizophrenia suffer from significant caregiver burden as measured by the BAS. Disability of mild-to-moderate degree was pervasively experienced by all the 52 participants.

The most powerful determinant of spousal caregiver burden was the degree of disability as measured by the IDEAS. The mediating effect of disability was greater than that of severity or duration of illness, socioeconomic level, or rural residence.

Mitigating caregiver burden is a feasible strategy to improve outcomes in schizophrenia. This study highlights the importance of disability in determining the extent of spousal caregiver burden and thereby points to the need for interventions that could limit or prevent caregiver burn out and the consequent attrition of sources of care and support for the sufferer.

### Limitations of the study

Since the study was carried out among spouses who accompanied patients attending outpatient reviews, the findings are applicable only to a hospital-based population. Duration of marriage, number of children, duration of caregiving, and coping strategies of caregivers that may influence spouses' burden appraisal were not within the scope of this study. The small sample size was yet another limitation. The study design excluded divorced and separated patients, thereby removing possibly the most burdened caregivers from the population under study. Gender difference in spousal burden could not be adequately analyzed since the greater burden among female spouses was not clinically significant. This could have been because of fewer female spouses than male spouses in the population under study.

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### Conflicts of interest

There are no conflicts of interest.

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The manuscript system ([www.journalonweb.com](http://www.journalonweb.com)) allows the authors to check and verify the accuracy and style of references. The tool checks the references with PubMed as per a predefined style. Authors are encouraged to use this facility, before submitting articles to the journal.

- The style as well as bibliographic elements should be 100% accurate, to help get the references verified from the system. Even a single spelling error or addition of issue number/month of publication will lead to an error when verifying the reference.
- Example of a correct style  
Sheahan P, O'leary G, Lee G, Fitzgibbon J. Cystic cervical metastases: Incidence and diagnosis using fine needle aspiration biopsy. *Otolaryngol Head Neck Surg* 2002;127:294-8.
- Only the references from journals indexed in PubMed will be checked.
- Enter each reference in new line, without a serial number.
- Add up to a maximum of 15 references at a time.
- If the reference is correct for its bibliographic elements and punctuations, it will be shown as CORRECT and a link to the correct article in PubMed will be given.
- If any of the bibliographic elements are missing, incorrect or extra (such as issue number), it will be shown as INCORRECT and link to possible articles in PubMed will be given.