


# Caregiver burden is associated with disability in schizophrenia: Results of a study from a rural setting of south India

International Journal of  
Social Psychiatry  
2015, Vol. 61(2) 157–163  
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DOI: 10.1177/0020764014537637  
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## Abstract

**Background:** Taking care of patients with schizophrenia is a major source of burden to the family. Research on burden experienced by family members of patients living in rural communities is sparse.

**Methods:** Data were obtained from a community intervention program for psychoses in a rural community of south India, where persons with severe mental disorders were identified, treated and followed up. As part of the program, caregivers of 245 schizophrenia patients were interviewed using the Burden Assessment Schedule. Psychopathology (Positive and Negative Syndrome Scale; PANSS), treatment status and disability (Indian Disability Evaluation and Assessment Scale; IDEAS) experienced by the patients were also assessed. Univariate and multivariate analyses were used to study the influence of different factors on the caregiver burden.

**Results:** Level of burden had a significant direct correlation with disability (Pearson's  $r = .35$ ;  $p < .01$ ) and severity of psychopathology ( $r = .21$ ;  $p < .01$ ). Duration of treatment had an inverse correlation with burden (Pearson's  $r = -.16$ ;  $p < .01$ ). Multivariate analysis revealed that total IDEAS score (Beta = .28;  $t = 4.37$ ;  $p \leq .01$ ), duration of treatment (Beta =  $-.17$ ;  $t = -2.58$ ;  $p = .01$ ), age of the family caregiver (Beta = .15;  $t = 2.4$ ;  $p = .02$ ) and gender of the patient (Beta =  $-.13$ ;  $t = -2.1$ ;  $p = .04$ ) were significant predictors of burden. The model including total IDEAS score explained 14% of variance (adjusted  $R^2 = .139$ ;  $p < .01$ ).

**Conclusion:** 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.

## Keywords

Schizophrenia, caregiver burden, disability, rural community

## Introduction

Burden experienced by families who care for schizophrenia patients is one among the many challenges of this disorder. Burden of care is a complex construct, which includes not only the physical and, economic impact but also, shame, embarrassment, feelings of guilt and self-blame. The burden may be objective (taking care of daily tasks, etc.) or subjective (caregiver's perception of burden) (Awad & Voruganti, 2008). Family caregivers might experience time lost from work, unreimbursed medical and other patient-related expenses, limited time for leisure and socializing, elevated symptoms of psychological distress and feelings of stigmatization, poorer quality of life, poorer self-rated health, chronic medical conditions, increased visits to a primary care physician, greater use of psychotropic drugs and increased risk of medical hospitalization (Perlick et al., 2006). Cultural factors could also play a role in the expression of caregiver burden,

as elucidated by Awad and Voruganti (2008). For example, White family members are more likely than the African Americans to feel burdened by their relatives' schizophrenia (Rosenfarb, Bellack, & Aziz, 2006). Likewise, a couple of more studies have shown that Hispanic families are more accepting of current disabilities and hope for the future (Jenkins, 1988, 1997).

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The issue of family burden assumes even more importance in the community context of low and middle income (LAMI) countries such as India, where families form the most important, and in many instances, the only part of the caregiving system for persons with severe mental illnesses including schizophrenia. Not surprisingly, as has been summarized in Table 1, a number of Indian studies have explored the issue of family caregiver burden in schizophrenia. All studies are cross-sectional in design. Only two studies examined the correlates of burden. Overall, family caregivers of patients with schizophrenia experienced greater burden than other disorders (with a notable exception of obsessive compulsive disorder). Spouses, particularly wives, of schizophrenia patients were found to experience greater burden.

All the studies were conducted in urban, academic centers; research on burden experienced by family members of patients living in rural communities is lacking. More than 70% of schizophrenia patients in India live in rural communities, and findings of hospital-based studies may not be easily generalized to such communities. In this report, we have presented the results of a study on caregiving burden experienced by family members of patients with schizophrenia living in Thirthahalli, a rural taluk (an administrative block) of Karnataka, a south Indian state.

## Materials and methods

### Subjects

The data for this study come from the CoInPsyD (Community Interventions in Psychotic Disorders: Relative Merits of Early Intervention; Thirthalli et al., 2009) program. This entails identifying, treating and following up all patients with schizophrenia in Thirthahalli taluk of south India. Our research team has been running this program for the past 9 years. Patients are followed up once in 2 to 3 months in their respective primary health centers; different research assessments were done once in 6 months, when patients are accompanied by their family members. Patients who are unwilling to receive treatment by the research team continue to consult their private psychiatrists. Both groups of patients – those receiving treatment by the research team as well as those receiving treatment from private psychiatrists are regularly assessed using standardized assessment tools.

Thirthahalli consists of 1,324 villages and a town that serves as the headquarters. The town has a population of 14,308 and the population of the whole taluk is about 150,000. We trained village health workers to identify patients with severe mental disorders in the community. The health workers maintain community survey registers, which contain details of the households under their care (a total of 29,432 households). Two trained research social workers referred to these survey registers and interviewed

the health workers regarding persons with symptoms of psychosis in each of the household. They were asked to refer all such patients, irrespective of their treatment status, to the study team. Research psychiatrists then screened these patients by using International Classification of Diseases (ICD)-10 (World Health Organization, 1992) criteria. The Mini International Neuropsychiatric Interview (MINI; Sheehan et al., 1998) was used to confirm the diagnosis.

We collected details of their family constellation. For assessing the burden of care, we interviewed the relatives/caregivers who took the maximum care of these patients. At the time of writing this report, 340 persons had been identified with an initial diagnosis of schizophrenia. We assessed the family burden of patients after they had completed 18 months of follow-up with the study team, by which time, the research social worker had adequate knowledge about, and rapport with, the family members. Nine among the 340 patients had no family members to provide details (they either lived alone or wandered around without stable housing arrangements). Rest of them lived with one or more family members. Among them, 16 had died within the follow-up period; in 7 patients, there was change in diagnosis; 21 patients had migrated out of the study area; 11 caregivers did not provide consent for assessment and 8 patients had no contact with their family members for a long time. In 23 of the remaining 268 patients (8.9%), the family members were unavailable at the time of assessment; caregiver burden could be assessed among 245 relatives (91.1%). This report examines the factors associated with caregiver burden in this cohort.

### Assessments

**Caregiver burden.** Two trained research social workers assessed family burden using the Kannada translation of the Burden Assessment Schedule (BAS; Thara, Padmavati, Kumar, & Srinivasan, 1998). This instrument rates burden experienced by the caregiver across 40 items that cover nine sub-domains: spouse-related, physical and mental health, external support, caregiver's routines, support of patient, taking responsibility, other relations, patient's behaviors and caregiver's strategy. Each of the 40 items is rated on a three-point scale marked 1–3, higher score indicating higher burden. The scale assesses both objective (e.g. family caregiver having time to look after his/her health, financial resources to care for the patient etc.) as well as subjective burden (e.g. spouse being affectionate, feelings of depression or anxiety and caregiver feeling isolated) experienced by the primary caregivers of mentally ill patients.

**Psychopathology.** Research psychiatrists used the Positive and Negative Syndrome Scale (Kay, Fiszbein, & Opler, 1987) to assess psychopathology. This extensively used 45-minute

**Table 1.** Studies from India focusing on burden among caregivers of patients with schizophrenia.

Authors and year	Aim	Methodology	Main findings
<b>Studies comparing burden among caregivers of schizophrenia patients and patients with other disorders</b>			
Chakrabarti, Raju, Kulhara, Avasthi, and Verma (1995)	Comparison of caregiver burden among relatives of patients with schizophrenia and bipolar disorder	Family caregivers of schizophrenia ( $n = 60$ ) and bipolar disorder ( $n = 78$ ) were interviewed using the Family Burden Interview Schedule (Pai & Kapur, 1981)	Caregivers of schizophrenia experienced more burden, though the pattern of burden was comparable between the two groups
Jayakumar, Jagadheesan, and Verma (2002)	Comparison of caregiver burden among relatives of patients with schizophrenia and OCD	Family caregivers of schizophrenia ( $n = 41$ ) and OCD ( $n = 30$ ) were interviewed using the BAS	Caregivers of patients with OCD experienced more burden in spouse-related and caregiver strategy-related domains. In all other domains, the experienced burden was comparable.
Gautam and Nijhawan (1984)	Comparison of caregiver burden among relatives of patients with schizophrenia and chronic lung disease	Family caregivers of schizophrenia ( $n = 25$ ) and chronic lung disease ( $n = 25$ ) were interviewed using a proforma specifically designed for the purpose of the study	Caregivers of schizophrenia experienced significantly greater burden across several domains
Koujalgi and Patil (2013)	Comparison of caregiver burden among relatives of patients with schizophrenia and depression	Family caregivers of schizophrenia ( $n = 100$ ) and depression ( $n = 100$ ) were interviewed using the FBIS	Caregivers of schizophrenia experienced significantly greater burden across several domains
<b>Studies comparing burden among different family caregivers of schizophrenia patients</b>			
Kumar and Mohanty (2007)	Comparison of caregiver burden among male and female spouses of schizophrenia patients	Male ( $n = 35$ ) and female ( $n = 35$ ) spouses of schizophrenia patients were compared using the BAS	Caregiver burden was greater among wives than among husbands of schizophrenia patients. Spouses living in nuclear families experienced greater burden than those living in joint families.
Rammohan, Rao, and Subbakrishna (2002)	Comparison of caregiver burden among spouses and parents of schizophrenia patients	Spouses ( $n = 24$ ) and parents ( $n=24$ ) of patients with schizophrenia were interviewed using the BAS and the Coping Checklist	Spouses experienced greater burden than parents. Patient's higher age, lesser educational level, lower functioning level and caregiver's use of denial as a coping strategy emerged as significant predictors of caregiver burden
<b>Path-analytic study of psychological morbidity among family caregivers of patients with schizophrenia</b>			
Kate, Grover, Kulhara, and Nehra (2013)	Path-analysis of caregiver burden among relatives of schizophrenia patients	Family caregivers ( $n = 100$ ) of patients with schizophrenia were interviewed using the FBIS, SPACE, IEQ, Coping Checklist, Social Support Questionnaire and GHQ	Burden was influenced by symptom severity, time spent per day in caregiving and coping strategies used; burden predicted psychological morbidity among caregivers

BAS: Burden Assessment Schedule (Thara, Padmavati, Kumar, & Srinivasan, 1998); FBIS: Family Burden Interview Schedule (Pai & Kapur, 1981); GHQ: General Health Questionnaire; IEQ: Involvement Evaluation Questionnaire; OCD: obsessive compulsive disorder; SPACE: Scale for Positive Aspects of Caregiving Experience

All are cross-sectional studies of outpatients attending urban, academic institutes.

**Table 2.** Socio-demographic details of caregivers.

Mean age (SD)		44.1 (14.5)
Females (n (%))		129 (52.7)
Relationship of caregivers (n (%))	Spouse	98 (40.2)
	Parent	59 (24.1)
	Sibling	36 (14.6)
	Children	36 (14.6)
	Others	16 (6.1)
Occupation of the caregivers (n (%))	Daily wage laborers	101 (41.2)
	Homemakers	35 (14.3)
	Agriculture	82 (33.5)
	Others <sup>a</sup>	34 (13.8)

<sup>a</sup>Including salaried jobs, businessmen, retired persons, students and so on.

interview schedule collects information from patients and caregivers to assess symptoms across three dimensions, positive, negative and general psychopathology.

**Disability.** The Indian Disability Evaluation and Assessment Scale (IDEAS; Rehabilitation Committee of the Indian Psychiatric Society, 2002) was used to assess the level of disability. The IDEAS had been originally developed for measuring and certifying disability for psychiatric patients in India. It assesses disability across four domains: self-care, interpersonal relationships, communication and understanding and work. Disability is scored from 0 to 4 for each domain (0 = *no disability*; 4 = *profound disability*) and the sum of the four item scores gives the total disability score. Global disability score is calculated by adding the total disability score and a score for the duration of illness (DOI score, which ranges from 0 to 4). For the purpose of this study, we analyzed only the total disability. The IDEAS has satisfactory face validity, criterion validity and internal consistency. Although originally meant for certifying disability of patients with psychiatric illnesses, it has been used for research purposes, and has been found to be sensitive in the identification of milder levels of disability as well (Mohan, Tandon, Kalra, & Trivedi, 2005; Thara, 2005). The IDEAS was also administered by research psychiatrists.

**Treatment.** At the time of recruitment into the program, patients and their family members were requested to provide all information pertaining to patients' mental illness. During the follow-up period, they were given the choice of obtaining treatment from either the study team or from private psychiatrists practicing in the region. The treatment details were noted. Efforts were made to impress upon the patients and their families the potential benefits of treatment in the follow-up. Around 90% of the patients received atypical antipsychotics. All patients were provided detailed psycho education about the possible causes, manifestations, treatment and outcome of schizophrenia. No other structured psychosocial interventions were provided.

**Table 3.** Correlation between total burden score and other variables.

	Pearson's R	p value
Age of the patient	.03	.69
Age of the caregiver	.14	.03
Total PANSS	.21	<.01
Positive subscale	.16	.02
Negative subscale	.22	<.01
General psychopathology subscale	.22	<.01
Duration of treatment in months	-.16	.02
Duration of illness	.02	.77
Total IDEAS	.35	<.01
Self-care	.29	<.01
Interpersonal	.30	<.01
Communication	.32	<.01
Work	.38	<.01

IDEAS: Indian Disability Evaluation and Assessment Scale; PANSS: Positive and Negative Syndrome Scale.

**Statistical analysis.** Student *t*-test or analysis of variance (ANOVA) and Pearson's correlation were used to evaluate the association of family burden score with other categorical and continuous variables, respectively. Stepwise multiple linear regression analysis was used to explore the predictors of burden.

**Ethical considerations.** The Institutional Ethics Committee of National Institute of Mental Health and Neuro Sciences (NIMHANS) approved this community intervention program. Written informed consent was obtained from all patients and/or their family members for treatment, follow-up and assessments.

## Results

### Subjects

*Mean* (standard deviation (*SD*)) age of the patients was 42.7 (11.6) years. Females formed 52% of the sample ( $n = 128$ ). *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). Socio-demographic details of caregivers are given in Table 2.

### Burden

The *Mean* (*SD*) total burden score for the entire sample was 63.08 (14.27). Details of its determinants appear in Table 3. The higher the disability, greater was the burden. Likewise, the higher the psychopathology and age of the caregivers, the greater was the burden. Duration of treatment had an inverse correlation with burden. Significantly more burden was experienced by the caregivers of male patients (*Mean* (*SD*) burden = 65.40(13.81)) than that of



female patients (*Mean (SD)* burden = 61.0(14.41);  $t = 2.5$ ;  $p = .02$ ). Burden experienced by the caregivers differed depending on their relationship with the patients. More severe burden was experienced if caregivers were spouses (*Mean* total BAS score = 70.9 (12.2)) than if they were parents (66.4 (14.6)), siblings/other relatives ((64.5(11.5)) or children (61.9 (11.1)) ( $F = 3.7$ ;  $df = 3$ ;  $p = .01$ ). Also, when patients were males, significantly more number of females were caregivers and vice versa (for male patients, 64.3% of the family caregivers were females, and for female patients, 70.4% of the family caregivers were males;  $\chi^2 = 30.39$ ;  $p < .01$ ). Overall, female caregivers tended to experience more burden when compared to their male counterparts ((*Mean (SD)* total BAS score = 64.68 (13.72) vs 61.41 (14.74) for female and male caregivers, respectively;  $t = -1.8$ ;  $p = .07$ ). Age of the patient and duration of illness did not have significant correlation with burden scores.

Since there was high correlation between PANSS total score and IDEAS total score (Pearson's  $r = .76$ ;  $p < .01$ ), we examined two models of predicting family burden by including variables that were significantly associated with total BAS in bivariate analysis in these models, each including PANSS total or IDEAS total scores. The other predictor variables were: age of the family caregiver, gender of the patient and duration of treatment. Both models were significant. The model including IDEAS explained 14% (adjusted  $R^2 = .139$ ) of variance. (Beta = .28;  $t = 4.37$ ;  $p \leq .01$ ). Total IDEAS score (Beta = .28;  $t = 4.37$ ;  $p < .01$ ), duration of treatment (Beta = -.17;  $t = -2.58$ ;  $p = .01$ ), age of the family caregiver (Beta = .15;  $t = 2.4$ ;  $p = .02$ ) and gender of the patient (Beta = -.13;  $t = -2.1$ ;  $p = .04$ ) emerged as significant predictors of total burden in this model. However, the model including PANSS total could explain only 3% (adjusted  $R^2 = .028$ ) of the variance. (Beta = .18;  $t = 2.63$ ;  $p < .01$ ). None of the other following variables predicted burden (gender of the patient (Beta = -.13;  $t = -0.91$ ;  $p = .07$ ), age of the family caregiver (Beta = .12;  $t = 1.73$ ;  $p = .08$ ) and duration of treatment (Beta = -.13;  $t = -0.81$ ;  $p = .07$ )).

## Discussion

In this study we studied the burden faced by the caregivers of patients with schizophrenia living in a rural South Indian community. Male gender of the patients, lesser duration of treatment, caregiver being a spouse, higher level of psychopathology and greater disability in patients were associated with greater burden among caregivers. Disability experienced by the patient appeared to be the most important factor associated with caregiver burden in this community. Disability and psychopathology are correlated; both are also potentially modifiable predictors (Thirthalli et al., 2009). Efforts in reducing the disability and symptom severity can hence be expected to reduce the

burden experienced by the caregivers. Another important predictor of burden was the age of the family caregiver. As age increases, it is conceivable that an individual is challenged by number of health-related (age-related medical problems) and other (for example, issues such as 'what after me', financial issues, issues of social support etc.) stressors. Since schizophrenia is a lifelong issue for the caregiver, it appears natural that the burden increases with aging of the caregivers. With regard to larger burden experienced by caregivers of male patients, it can be noted that spouses experienced more burden and that female caregivers tended to experience more burden than their male counterparts. In the Indian socio-cultural context, when males are patients, female spouses would have to don dual roles of managing the household as well as being the breadwinners. This is consistent with the finding of Kumar and Mohanty (2007) where wives as caregivers experienced more burden than husbands as caregivers.

The mean total burden of the families in our study was slightly lower than a couple of studies (Creado, Parkar, & Kamath, 2006; Kumar & Mohanty, 2007). This is possibly because of the differences in the setting in which the studies were conducted, as patients attending hospitals are likely to be more severely ill than those living in the community. Spouses had greater burden than other caregivers. This, again, may be a function of the setting in which families live – in rural families, the roles assumed by the spousal caregivers may be associated with different levels of burden. Consistent with this, age of the patient and duration of illness did not have any effect on the caregiver burden in our study.

Strengths of the study included the following: first, we studied patients who were living in the community. Only 44% of these patients were in contact with psychiatric centers when they were recruited into the study (Thirthalli et al., 2009). Studies conducted in hospitals would have missed them. Second, we conducted this study in a rural area. More than 70% of Indian population lives in rural areas and the results are thus generalizable to a larger set of population. Third, in this study, trained raters and psychiatrists used standardized tools for establishing diagnosis and assessing psychopathology, disability and burden. However, we could not assess about 10% of the eligible families. There is a possibility that the burden faced by their families may be different from that faced by those whose burden could be assessed. This limitation should be considered while interpreting the results of this study.

The importance of the need to focus on outcomes beyond mere symptom reduction has been stressed (Burns & Patrick, 2007; Waghorn, Chant, White, & Whiteford, 2004). Our earlier work has shown that patients treated at the community level are associated with lesser disability (Thirthalli et al., 2010). These benefits can be maintained over extended periods of time also (Suresha et al., 2012; Thirthalli et al., 2009). Family

burden is significantly correlated with disability in this sample. Additionally, those on treatment for longer duration had lesser burden. It may be concluded that the influence of treatment on family burden could be partly mediated through its influence on the disability. Thus, treatment at the community level appears to reduce both disability and family burden, and not merely the symptoms. Furthermore, patients received little beyond antipsychotics and family psycho education. With greater psychosocial interventional inputs, we may expect greater reduction in disability and burden.

In conclusion, this study on families of patients living in a rural community suggests that burden experienced by the family members is strongly associated with the disability suffered by the patients and not on the severity of their symptoms. Efforts to treat schizophrenia in the community should target not just symptom reduction, but should also aim to reduce disability.

### Acknowledgements

We gratefully acknowledge Ms Suma K, who was one of our project staff. Her role included coordinating the patient follow-ups, psycho education, coordinating visits of the team members, making home visits, writing letters and making phone calls. She also did assessments related to family burden.

### Funding

This project was funded by National Mental Health Program, Government of India's research grants to B.N.G. (2005–2007).

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