



Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in the caregivers of schizophrenia



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ABSTRACT

Aim: To evaluate the relationship of caregiver burden as assessed by using Hindi Involvement Evaluation Questionnaire (IEQ) with coping strategies, social support, psychological morbidity, and quality of life of caregivers of patients with schizophrenia. Additionally, the relationship of caregiver-burden with sociodemographic variables, and clinical variables, including severity of psychopathology and level of functioning of patients, was studied.

Methodology: The study included 100 patients with schizophrenia and their caregivers recruited by purposive random sampling.

Results: Among the four domains of IEQ, highest number of correlations emerged with tension domain. Tension domain had positive correlation with the caregiver being single, time spent in caregiving per day, and use of avoidance, collusion, and coercion as coping strategies. Additionally, tension domain was associated with poor quality of life in all the domains of WHO-QOL Bref and was associated with higher psychological morbidity. Worrying urging-I domain of IEQ correlated with frequency of visits, higher use of problem focused coping and poor physical health as per the WHO-QOL Bref. Worrying urging-II domain of IEQ had positive correlation with higher level of positive symptoms, lower level of functioning of the patient, younger age of caregiver, caregiver being unmarried, and higher use problem focused and seeking social support as coping strategies. Supervision domain of IEQ correlated positively with lower income, being an unmarried caregiver, from an urban locality and non-nuclear family. Supervision domain was associated with poor physical health as assessed by WHO-QOL Bref.

Conclusion: Caregiving burden, especially tension is associated with use of maladaptive coping strategies, poor quality of life and higher level of psychological morbidity in caregivers.

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1. Introduction

Schizophrenia is a severe mental disorder, which places a considerable burden on the caregivers. Families experience a lot of physical, emotional and financial distress due to a patient's abnormal behavior, and social and occupational dysfunction. In countries like India, where rehabilitation services are almost non-existent and there is no social security system, the role of the family becomes more important.

Many studies from India have evaluated burden perceived by the caregivers of schizophrenia and these show that schizophrenia is a burdensome illness. Studies which have compared the burden

of caregiving of schizophrenia with other psychiatric disorders, suggest that schizophrenia is more burdensome than recurrent depressive disorder (Chakrabarti et al., 1995), bipolar disorder (Chakrabarti et al., 1995; Chakrabarti and Gill, 2002), obsessive compulsive disorder (Thomas et al., 2004) and other neurotic disorders (Chakrabarti and Kulhara, 1999).

However, previous studies from India have mostly used the Family Burden Interview (FBI) (Pai and Kapur, 1981) or Burden Assessment Schedule (BAS) (Thara et al., 1998), which are interviewer based instruments for assessment of burden in caregivers. The primary focus of the FBI is on objective burden, and it is relatively inadequate with regards to assessment of the subjective consequences of caregiving, which is assessed by only one item of the instrument. On the other hand, BAS assesses both objective and subjective burden, but still the major emphasis is on the objective burden.

Over the years, several new burden-assessment instruments have been developed. One such instrument, the Involvement

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Evaluation Questionnaire (IEQ) was developed to assess the consequences of caregiving, and is based on the stress-appraisal-coping model (Schene et al., 1996, 1998). Being a self report scale, the IEQ evaluates the ‘consequences of caregiving’ and reflects the caregivers’ perception of burden without distinguishing between the objective and subjective aspects. Recently this instrument was adapted and evaluated for the psychometric properties in the Indian setting and has been shown to have good internal consistency and reliability (Grover et al., 2011).

Studies suggest that the level of caregiver burden is commonly associated with levels of dysfunction or disability, severity of symptoms and duration of illness (Raj et al., 1992; Chakrabarti et al., 1995; Kataria et al., 2002; Rammohan et al., 2002a; Saldanha et al., 2002; Creado et al., 2006; Thomas et al., 2004; Kalra et al., 2009). Findings with regard to association of burden with sociodemographic variables have been inconsistent. The general trend is that the caregiver burden is higher when the patient is male, caregiver is female, caregiver is less educated and in those from a low-socioeconomic background (Roychaudhuri et al., 1995; Rammohan et al., 2002a,b; Kumar and Mohanty, 2007; Nehra et al., 2006; Chakrabarti, 2010). Studies evaluating the relationship of burden with coping suggest that uses of denial and other emotion-focused strategies are associated with higher burden (Sekharan et al., 2001; Rammohan et al., 2002a; Creado et al., 2006). However, as mentioned, most of the Indian research is based on instruments which mainly assess objective burden, while the subjective burden is rarely being the major focus.

As there is lack of data on subjective burden as a consequence of caregiving on schizophrenia from India, the present study, aimed to (1) Evaluate the relationship of caregiver-burden and coping strategies, social support, psychological morbidity and quality of life of caregivers of patients with schizophrenia. (2) Study the relationship of caregiver burden with sociodemographic variables and clinical variables including severity of psychopathology and level of functioning of patients with schizophrenia.

2. Methods

2.1. Setting and study population

The study was conducted in the psychiatry department of a multi-specialty hospital catering to a large section of the population of north-India. The study was approved by the Ethics Committee of the Institute. All participants were recruited after obtaining proper written informed consent. A cross-sectional study design was employed. The patients were assessed only once at the time of intake into the study. The study included 100 patients with schizophrenia along with their caregivers. The sample was selected by purposive random sampling, i.e. to get the study sample of 100 patients, 200 patients fulfilling the inclusion and exclusion criteria were approached and of these 100 were included in the study based on the pre-generated randomization number.

2.2. Inclusion and exclusion criteria

Inclusion criteria for the patients were a diagnosis of schizophrenia as per DSM-IV (American Psychiatric Association, 1994), age between 20 and 60 years and with an illness of 2–10 years duration. Patients with comorbid chronic physical, psychiatric, substance dependence (except tobacco dependence) disorders and organic brain syndromes were excluded. Patients who had a family member with a diagnosed chronic physical illness or comorbid psychiatric disorder staying in the same dwelling unit were also excluded.

For this study, a primary caregiver was defined as a ‘‘person living with the patient and intimately involved in the care of

the patient for at least one year, i.e., looking after her/his daily needs, supervising the medications, bringing the patient to the hospital, staying with the patient during inpatient stay and maintaining liaison with the hospital staff’’. To be included in the study, the caregivers were required to be older than 18 years of age, involved in the continuous care of patient for at least the last one year, free from any diagnosed physical or psychiatric disorder (other than tobacco dependence) and were required to be able to read Hindi.

2.3. Instruments

Severity of psychopathology of the patients was assessed on Positive and Negative Syndrome Scale for Schizophrenia (PANSS) (Kay et al., 1987).

2.3.1. Hindi Version of Involvement Evaluation Questionnaire (Grover et al., 2011)

Caregiver burden was assessed by using IEQ. One of the versions of IEQ, commonly used in Europe in the EPSILON study, known as IEQ-EU, has a core module which assesses ‘‘caregiver-burden’’ and consists of 31 items, each rated on 5-point Likert scales (van Wijngaarden et al., 2000). In our previous study, we adapted and translated the IEQ-EU into Hindi and evaluated its psychometric properties (Grover et al., 2011). The Hindi-IEQ has been found to have significant Pearson’s correlation coefficients ($p < 0.05$) and intra-class correlation coefficients for each item (0.76–1.0) and subscales, indicating a satisfactory level of agreement between the Hindi and English versions. Test-retest reliability for all items of the Hindi-IEQ was adequate, and internal consistency (Cronbach’s alpha – 0.89) and split-half reliability (Spearman–Brown coefficient – 0.68) of the Hindi-IEQ were also satisfactory. Factor analysis of the scale yielded four subscales covering 29 items. These four factors were labeled as tension (10 items), worrying-Urging-I (10 items), worrying-Urging-II (6 items) and supervision (3 items) (Grover et al., 2011).

2.3.2. Global Assessment of Functioning Scale (GAF) (Endicott et al., 1976)

The GAF provides measures of overall functioning relating to psychiatric symptoms. It is a clinician-rated, 100 point scale based on all available information with clear description of each 10-point intervals.

2.3.3. Social Support Questionnaire-Hindi Adaptation (Nehra et al., 1996)

Social support was assessed by using a Hindi adaptation (Nehra et al., 1996) of the Social Support Questionnaire (SSQ) by Pollack and Harris (1983).

2.3.4. The Coping Checklist-Hindi version (Nehra et al., 2002)

This was used to assess the coping strategies used by the caregivers. It is a modified Hindi version of the coping check list of Sczufca and Kupiers (1999). It was modified by Nehra et al. (2002). It consists of 14 items divided into 5 domains/subscales: problem focused (3 items), seeking social support (4 items), avoidance (5 items), collusion (1 item), coercion (1 item). The items are rated on a three point scale (0 – never; 1 – sometimes and 2 is always used). There is good correlation between most of the items in the English and Hindi version. Cronbach’s alpha of the scale is 0.62 indicating acceptable level of internal consistency

2.3.5. WHO Quality of Life – Bref Version (Hindi Version) (Saxena et al., 1998)

This scale was used to assess the Quality of Life (QOL) of the caregivers. It is the only QOL instrument that has been designed as

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