A Study of Stress in Caregivers of Patients with Schizophrenia

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Abstract
Background: Schizophrenia is a disorder with psychological distress not only for the patients but also for the caregivers. The caregivers receive little support from medical services.
Aim: To assess the stress level in caregivers of patients with schizophrenia.
Materials and Methods: It was a descriptive hospital based study carried out in Psychiatry Department of Anugrah Narayan Medical College and Hospital, Gaya, Bihar after obtaining Ethical Committee approval. Hundred caregivers were included in the study during a period of six months. Socio demographic variables were recorded on specially designed Performa. Stress level was assessed by using Self Report Questionnaire (SRQ-20) with a cut off score of 9 being taken as stressed. Data was evaluated using the Statistical Package for the Social Sciences (SPSS Inc. version 17.0).
Results: Eighty-five (85%) caregivers were males and 15 (15%) were females. Fifty-six (56%) caregivers were having score of more than 9 on SRQ-20.
Conclusions: Psychological distress was found in a significant number of the caregivers of patients with schizophrenia. Our findings emphasise importance of screening and psychiatric counselling of this vulnerable population and highlights the burden of care in this often neglected population and the need for the psychological care of the caregivers.
Keywords: Stress, Caregivers, Schizophrenia.

Introduction
In the World Health Report, schizophrenia is listed as the 8th leading cause of DALYs worldwide in the age group 15-44 years.¹ It has been recognized as a devastating disorder for patients and their families for ages. Caregivers are people who "provide unpaid care by looking after an ill, frail or disabled family member, friend or partner".² Deinstitutionalization in psychiatric care approach has shifted much of the burden of care of patients with schizophrenia from mental institutions to the family.³

Schizophrenia is a chronic mental illness with a devastating impact on the patient as well as the whole family. The capacity for social relationship often gets diminished, and opportunities for
working for livelihood gets reduced. Recent treatment advancements have helped a large number of patients to recover significantly, but many still continue to show deficits in several areas of functioning. Patient's relatives experience a range of emotions, like burden of care with increased responsibilities. Similar to patients, they too feel isolated and suffer stigmatisation by society. If care giving is prolonged, sense of burden which is throughout a persons life as ailment is often a chronic one prevails, and therefore the psychological stress and problems get exacerbated. As things do not get better with time, a sense of hopelessness begins. A further difficulty is that caregivers find they have no choice but to have a compromised life. All these aspects though painful can at times be a source of satisfaction. Caregiver burden has thus been defined as "the presence of problems, difficulties or adverse events which affect the lives of psychiatric patients significant others (e.g. members of the household and/or the family)."

Indian caregivers have always been involved in the care and treatment of people with mental illness as bonding and social system of care is stronger in Indian scenario with the family as the primary care provider in contrast to the West. This is due to the social and cultural milieu as well as the inadequate existing mental health infrastructure. Families in India have a prominent role to play in decisions regarding the treatment process and supervision of patients and providing them emotional support.

Material and Methods
It was a descriptive hospital based study carried out in Psychiatry Department of Anugrah Narayan Medical College and Hospital, Gaya, Bihar after obtaining Ethical Committee approval. Hundred caregivers were included in the study during a period of six months. Socio-demographic variables were recorded on specially designed proforma. Stress level was assessed by using Self Report Questionnaire (SRQ-20) with a cut off score of 9 being taken as stressed. Data was evaluated using the Statistical Package for the Social Sciences (SPSS Inc. version 17.0).

Results
A total of 100 caregivers who accompanied patients with schizophrenia in Psychiatry Department of Anugrah Narayan Medical College and Hospital, Gaya, Bihar after obtaining Ethical Committee approval and satisfied the study criteria which included the primary care givers of patients in the age group of 18-65 years of either sex were included. Those who themselves had any known major physical or psychiatric disorder, mental retardation or those not consenting for study were excluded from the study. Mean age of the caregivers was 44.44±12.24 years. Eighty-five (85%) caregivers were males and 15 (15%) were females. Fifty-six (56%) caregivers had score of more than 9 on SRQ-20. The duration of the care giving showed that 8 (8%) caregivers had been providing care for less than 06 months, 12 (12%) for less than 12 months, 27 (27%) for less than 18 months, 11 (11%) for less than 24 months and 42 (42%) for more than 24 months. In 53 (53%) of the patients caregivers were parents, 27 (27%) were siblings, 11 (11%) were children and 9 (9%) were others.

Table-1: The socio-demographic profile of the caregivers of patients of Schizophrenia (n=100):

| Socio-Demographic Profile | Number of Caregivers | Percentage (%) |
|---------------------------|----------------------|---------------|
| Gender                    |                      |               |
| Male                      | 85                   | 85            |
| Female                    | 15                   | 15            |
| Parents                   | 53                   | 53            |
| Siblings                  | 27                   | 27            |
| Children                  | 11                   | 11            |
| Others                    | 9                    | 9             |
| Relationship              |                      |               |
| <6 months                 | 8                    | 8             |
| 6 months-12 months        | 12                   | 12            |
| 12 months-18 months       | 27                   | 27            |
| 18 months-24 months       | 11                   | 11            |
| >24 months                | 42                   | 42            |

Discussion
Majority of Indian patients with psychiatric disorders remain with their families and they are the caregivers for them. As a result of the chronic
and consistent support required for these patients, the care givers are at risk of developing psychological distress, anxiety and depression.\textsuperscript{9} This distress varies in accordance with type of psychiatric illnesses and also their severity.\textsuperscript{10,11} Psychological distress in caregivers is reported in all cultures.\textsuperscript{12} The results of this study is consistent with previous studies done in other countries. Majority of the caregivers (56\%) were found to have a score of 9 or more on SRQ-20 and were found to be distressed. This higher psychological distress might be because of the study design (hospital based), inclusion of only those caregivers who were living with the patient or might had been because the patients coming to hospital are more disturbed than those in the community. It needs further evaluation whether this higher prevalence is similar to prevalence of distress in from the community sample for which further studies with larger sample size needs to be planned in future.

In this study mean age of the caregivers was 44.44±12.24 years. The difference could be because we did not include caregivers above the age of 65 years in our study while few other studies have included all age groups. Majority of patients were accompanied by male caregivers and this might have had a cultural reason. Other important considerations are the hospital based study and the studied sample not been true representative of the community.

**Conclusion**

The family constitutes an important support system in the care of the mentally ill in the community specially in our country. Mental health professionals need to take care of this important aspect of caregivers burnt out, identify the warning signs of stress in the caregivers. As shown by our study, a significant number of caregivers are themselves in need of care as caring for a loved one with a severe mental health disorder or psychotic illness like schizophrenia can be challenging; so mental health professionals should take special care of them. Future studies with larger sample size should be planned to address this important but often neglected aspect.

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