



A STUDY OF THE BURDEN OF CARE AND THE NEEDS OF CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA

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ABSTRACT

Background: There were very few Indian studies regarding caregiver burden and needs of caregivers in patients of schizophrenia.

Methodology: The study evaluated socio-demographic data, caregiver burden, caregiver needs and their associations in caregivers of schizophrenia.

Conclusions: The mean age of the caregivers was 51 years. There were equal number of males and females. Most of the caregivers were married, parents of the patient, Hindu by religion and belonged to the lower middle class. Most of the caregivers felt moderate to severe burden. The most frequently expressed need (85%) was for effective doctor patient skills. Other expressed needs were those for correct cognitive disorder management (83.33%), correct behavioral disorder management (81.67%), information about applying for economic help (76.67%) and emotional support for problems pertaining role change (80.00%).

Implications: These are important implications for mental health services, training of mental health professionals, research and policy guidelines.

KEYWORDS : "Burden of care", "needs", "caregivers", "Schizophrenia"

Introduction:

Schizophrenia is a clinical syndrome of variable but profoundly disruptive psychopathology that involves cognition, emotion, perception and other aspects of behaviour. The usual course of schizophrenia is one with exacerbations and remissions. These take a toll on the caregivers' health in the form of subjective burden, depression, distress and reduced quality of life.^[1]

Caregivers provide various types of services to the patient, which may be undemanding (like driving them to their appointment or other places) or highly demanding (like bathing or feeding them). As disease severity progresses, the demands on caregivers for services increases.^[1,2,3,4] This results in the development of a stressful psychological state or caregiver burden, often found in persons caring for a patient with severe mental illness. Some caregivers may report physical burden, emotional stress or financial strain.

Caregivers' sense of well-being may decide how long patients with schizophrenia reside in the community before being shifted to long term care institutions.^[1,5,6] The higher the perceived burden of care by the caregiver, the more likely it is that care in the community will be terminated.^[5,6]

If caregivers are to provide services to the patients, not only do they have to be aware of their patients' needs but also their own needs. Caregivers often require emotional support, information about the patient's illness and psycho-education so that they can effectively provide care and support to the patients. Unmet needs may themselves add to caregiver burden.^[7]

There are few studies regarding caregiver burden and their needs in caregivers of patients with schizophrenia. Most are foreign studies.^[1-6,8-13] This study will evaluate socio-economic factors, caregiver burden, caregiver needs and their associations in caregivers of patients with schizophrenia.

Aim:

To study the burden of care and the needs of caregivers of patients with schizophrenia

Objectives:

- To study the socio-demographic factors in caregivers of patients with schizophrenia
- To study the burden of care on caregivers of patients with schizophrenia
- To study the needs of caregivers of patients with schizophrenia
- To study the socio-economic data, caregiver burden, caregiver needs and their associations, if any, in caregivers of patients with schizophrenia

Materials & method:

Sample: The study was conducted on caregivers of patients with schizophrenia at a tertiary care hospital.

Type of study:

Cross-sectional in nature

Sample size:

60 caregivers of patients with schizophrenia

Inclusion criteria:

1) Patients with schizophrenia:

- Diagnosed as per ICD 10 classification by two qualified psychiatrists
- Age \geq 18 years
- Living with a family member for at least 1 year

2) Caregivers:

- Living with the patient for at least 1 year
- Spending more time with the patient than other family members
- Age \geq 18 years
- Caregivers who give consent
- Caregivers who could be interviewed

Exclusion criteria:

1) Patients:

Patients with co-morbid psychiatric or medical disorders

2) Caregivers:

Caregivers with co-morbid psychiatric or medical disorders

Tools:

- ICD 10 diagnostic criteria for research^[17]
- Kuppuswamy's socio-economic scale (Revised version January 2017)^[18]
- Positive and Negative Syndrome Scale (PANSS)^[19]
- Mini International Neuropsychiatric Interview PLUS^[20]
- Zarit burden interview (ZBI)^[21]
- Caregiver needs assessment questionnaire^[22]

Methodology:

The study was conducted on 60 caregivers of patients diagnosed with schizophrenia as per ICD 10 diagnostic criteria. The study protocol was approved by the institutional ethics committee. The patients and relatives were given information on the nature of the study and if they were willing, then their consent was recorded in the mother tongue of the caregiver/patient. The caregivers were interviewed and their socio-demographic data was recorded as per Kuppuswamy's scale. The Zarit burden interview and the caregiver needs assessment questionnaire

were administered to the caregivers. The results were tabulated and statistical analysis was done.

Observation and results:

Table 1: Socio-demographic data of caregivers & patients:

a) Caregivers:	
Age:	Percentage of caregivers
<20	1.67
20-30	8.33
30-40	15.00
40-50	20.00
50-60	26.67
60-70	21.67
70-80	5.00
>80	1.67
Gender:	
Male	50.00
Female	50.00
Relation to patient:	
Mother	31.67
Father	25.00
Wife	11.67
Husband	11.67
Brother	6.67
Sister	5.00
Daughter	3.33
Son	1.67
Cousin	1.67
Grandfather	1.67
Education:	
Illiterate	33.33
Literate	20.00
Secondary education	11.67
High school education	13.33
Intermediate	13.33
Graduate	8.33
Postgraduate	0.00
Socioeconomic class:	
Lower	6.67
Upper lower	73.33
Lower middle	13.33
Upper middle	6.67
Upper	0.00
b) Patients:	
PANSS scale:	Mean
Y P	18.18
Y N	17.73
Y G	32.52
Y Total	68.43

Caregivers with higher income ($r=-0.34, P<0.01$), better education ($r=0.30, P<0.05$) and a higher socioeconomic class ($r=-0.35, P<0.01$) tended to have lower caregiver burden. The caregivers of patients with higher positive symptom score on PANSS had higher burden ($r=0.27, P<0.05$).

Table 2: Degree of burden among caregivers

Degree of Burden	%
No or little	20.00
Mild-moderate	38.33
Moderate-severe	41.67
Severe	0.00

Table 3: Needs of caregivers

Need expressed	%
Knowing the services available	63.33
How to apply for economic help	76.67
How to apply for nursing home or day care accommodation	38.33
Knowing about foundations and institutions	66.67
Knowing the exact diagnosis	60.00
Knowledge about schizophrenia	60.00
Pharmacological therapy	60.00
Effective doctor-patient skills	85.00
Correct cognitive disorder management	83.33

Correct behavioral disorder management	81.67
Correct functional disorder management	76.67
Coping with stress	53.33
Emotional reaction elaboration	60.00
Problems accepting illness	8.33
Problems pertaining role change	80.00
End stage support	16.67
Respite care accommodation	46.67

The need for effective doctor-patient skills ($r=0.26, P<0.05$) correlated positively with male caregivers. The duration of illness correlated negatively with the needs for knowing the exact diagnosis ($r=-0.33, P<0.05$), knowledge about pharmacological ($r=-0.35, P<0.01$) and need for effective doctor-patient skills ($r=-0.27, P<0.05$).

The positive scores on PANSS correlated significantly with caregiver burden ($r=0.27, P<0.05$), the need for knowing the exact diagnosis ($r=0.27, P<0.05$), the need for information regarding pharmacological therapy ($r=0.35, P<0.01$), the need for effective doctor-patient skills ($r=0.29, P<0.05$) and the need for respite care accommodation ($r=0.26, P<0.05$).

OPD patients correlated negatively the need for knowing the exact diagnosis ($r=-0.43, P<0.01$), the need for knowing more about the illness ($r=-0.51, P<0.01$), the need for more information about the pharmacological therapy ($r=-0.43, P<0.01$), the need for effective doctor-patient skills ($r=-0.38, P<0.01$), the need for correct functional disorder management ($r=0.65, P<0.01$), the need for emotional support for problems in accepting the illness ($r=-0.36, P<0.01$), and the need for respite care accommodation ($r=-0.26, P<0.05$).

Also, caregiver burden correlated positively with the needs for information about economic help ($r=0.38, P<0.01$), information about applying for nursing home or day care accommodation ($r=0.40, P<0.01$), knowledge about pharmacological therapy ($r=0.30, P<0.05$), effective doctor-patient skills ($r=0.38, P<0.01$), emotional support for coping with stress ($r=0.34, P<0.01$), and respite care accommodation ($r=0.41, P<0.01$).

Discussion:

Our study evaluated the socio demographic data, the burden of care, the needs of caregivers and their associations on 60 caregivers of patients with schizophrenia at a tertiary care hospital.

Socio-demographic data:

26.67% of the caregivers in our study were in the age group of 51 to 60 years, with an equal number of males (50%) and females (50%). Most of the caregivers (55.9%) were the parents of the patients. The majority of the caregivers were illiterate (33.33%). 70% of the caregivers were employed. As per the Kuppaswamy scale, most of the caregivers were from the lower middle class (73.33%).

Our findings compare with Hidru et al, Adeosun Yeh et al, Winefield and Harvey, Parabiaghi et al and Jagannathan et al.^[1,4,6,7,14]

Our study compares with the hospital based Indian studies and a few hospital based foreign studies. However, unlike our study, most studies had more female caregivers.^[1,3,6,9,11,12] This was because our sample was mostly of caregivers of indoor patients.

Caregiver burden:

In our study, the mean ZBI score was 37.96. 20% caregivers felt little or no burden, 38.33% felt mild to moderate burden and 41.67% felt moderate to severe burden. No caregiver felt severe burden.

Our findings compare with Hidru et al, Shamshei et al and Mandal al.^[1,3,15] This study thus compares with the hospital based foreign studies and the hospital based Indian studies.

Caregiver needs:

In our study, caregivers expressed the needs for effective doctor-patient skills, correct cognitive disorder management, correct behavioural disorder management, emotional support for problems pertaining role change, information on how to apply for economic help and that for correct functional disorder management more frequently. Our findings compare with Yeh et al Jagannathan et al and Kajawu et al.^[5,11,14]

The needs expressed in our study compare with the needs expressed in the hospital based Indian study.^[15] Many of the needs expressed in the hospital based foreign studies and the special study are also similar to those in our study.^[5,6,11,13]

Associations:

In our study, caregivers with higher duration of caregiving and higher positive scores had more caregiver burden.

Caregivers with more caregiver burden reported more number of needs. Some of the needs in our study compare with male caregivers and duration of illness.

Our findings compare with Hidru et al Parabiaghi et al, Yeh et al and Sono et al.^[1,5,7,13]

The associations with caregiver burden found in our study compare with those found in the hospital based foreign studies.^[1,3,4,9] The associations with caregiver needs found in our study compare with those found in the hospital based foreign studies and the special study.^[5,6,13]

Limitations:

Our study evaluated 60 caregivers of patients of schizophrenia at a tertiary care hospital. This may not be representative of all the caregivers of patients of schizophrenia in the country at large. A larger study of the patients of schizophrenia at different tertiary care hospital in the country needs to be undertaken. Ours was a study of relatively short duration.

Strengths:

This is a well-designed cross sectional study carried out on a group of caregivers of patients of schizophrenia at a tertiary care hospital. We used standardized tools such as MINI PLUS, ICD-10 diagnostic criteria, Positive and negative syndrome scale (PANSS), Kuppaswamy socioeconomic scale, the Zarit Burden Interview and the caregiver needs assessment questionnaire. Our study highlights the differences between foreign based studies, Indian studies and special studies. It also highlights the socio-cultural factors of caregivers of patients with schizophrenia in the Indian setting.

Conclusion:

In our study, 60 caregivers of patients of schizophrenia were studied at a tertiary care hospital. The following are the conclusions:

Most of the caregivers were in the age group of 51 to 60 years. There was equal number of male and female caregivers. Most of the caregivers were married. Most of the caregivers were illiterate. Most of the caregivers belonged to the upper lower class. The majority of the caregivers were the parents of the caregivers.

There were more admitted patients than OPD patients. Most of the patients were diagnosed with Paranoid type of schizophrenia.

Most of the caregivers felt moderate to severe burden. The most commonly reported need was that for effective doctor-patient skills while the least expressed need was that for emotional support for problems in accepting the illness. There were significant associations between burden of care and education level of caregivers, their income, their socioeconomic class, time spent caring for the patient, positive PANSS scores and the total number of needs. The various needs expressed by caregivers were associated with the time spent caring for the patient, number of hospitalizations, PANSS scores, OPD patients and caregiver burden.

Implications:

Our study has implications for mental healthcare services, training of mental health professionals, research and policy decisions for caregivers of patients with schizophrenia.

Services:

This study will help in planning of services for caregivers of patients with schizophrenia.

Training:

Mental healthcare professionals need to be aware of the burden of care and the needs of caregivers in caregivers of patients with schizophrenia so they can apply suitable interventions.

Research:

Further research needs to be done and appropriate psychometric assessment tools in regional languages should be made available for assessing the burden of care in caregivers of schizophrenia.

Policy:

This will help in making suitable guidelines and policies for caregivers of patients with schizophrenia.

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