Research Paper **Psychology**

Caregiver Burden in Family Members of Patients With Mental Illness

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ABSTRACT

Aims: To quantify caregiver burden and its associated factors among primary caregivers of persons with mental illness.

Methods: After getting Institutional Ethics Committee (IEC) clearance and informed consent, a cross sectional study (N=100) was done with the caregivers of mentally ill patients who attended psychiatric Outpatient department in a tertiary care hospital from January 2014 to September 2015.Burden Assessment Schedule (BAS) was administered to assess caregiver burden in five domains. The higher scores indicate higher degree of burden.

Chi square test was done to find association between independent variables and outcome (caregiver burden).

Results: High caregiver burden on caregivers belonging to middle and lower socio economic status (x2= =11.318; p=0.03). Caregivers wellbeing is affected significantly if the illness duration is more than 1 year (x2= 7.174; p=0.007). Psychotic illnesses have a higher impact on the wellbeing of caregivers than the Neurotic illnesses (x2= 13.500; p=.000).

KEYWORDS : Caregiver burden, Psychosis, Neurosis

Introduction

Caregiver can be anyone who assists and provides support to a person who needs care. Burden can result in caregivers who are in contact with patients suffering from mental illness.[1, 2]Family caregiver burden is the difficulties, problems and negative life events that influence the life of family members caring for a loved one with mental illness.[3]Caregiver burden can be subjective burden and objective burden.[4]Family members are usually the primary caregivers for patients with mental illness.[5] Caregivers of the patients with mental illness carry a huge emotional burden which influences the care provided by them. Caregiver burden in families is often overlooked. Identifying and addressing the caregiver burden can have an influence on relapse rate reduction.

As there are relatively few Indian studies in this area,[6]this study was undertaken to quantify caregiver burden among primary caregivers of persons with mental illness and to find out the relationship between socio-demographic data, clinical variables and the outcome variable (caregiver burden).

Methodology

After getting Institutional Ethics Committee clearance, a cross sectional study (N=100) was done with the caregivers of mentally ill patients who attended psychiatric Outpatient department in a tertiary care hospital from January 2014 to September 2015. After obtaining informed consent, patients of age group 18 to 55 years were included. We also included patients who were on active treatment during the study. Patients with substance use disorders and co-morbid severe medical and surgical illnesses were excluded.

Socio demographic profile of the patients and caregivers, clinical data of the patients were recorded. The psychiatric diagnoses of the pa-

tients were coded according to International classification of diseases (ICD 10). For statistical convenience, patients with obsessive compulsive disorder, anxiety disorder, depressive disorder, and bipolar depression were grouped under neurosis (n=50). Patients diagnosed as mania with psychotic symptoms, acute psychosis, schizotypal, schizophrenia, persistent delusional disorder, psychosis NOS were grouped under psychosis (n=50).

Then, we administered the scale BAS to assess caregiver burden of the patients with mental illness. It is a 20 question scale developed by H. Sell, R.Thara et al,[7]in association with SCARF (schizophrenia research foundation) and WHO (regional office for south east Asia, new Delhi 1998) to assess caregiver burden. The questionnaire measures the degree of burden in five domains such as Impact on wellbeing, Impact on marital relationships, impact on relations with others, appreciation of caregiving and perceived severity of the disease with the maximum score of 12 in each domain and overall score of 60.The higher scores indicate higher degree of burden**.** Descriptive statistics was done to describe the socio - demographic data, patient diagnosis, burden assessment schedule. Inferential statistics by using chi square test as a test of statistical significance was done to find whether there was any association between the independent variables and the outcome or dependent variable (caregiver burden). The 'p' value less than 0.05 was considered as statistically significant.

Results
Descriptive Statistics:
Mean age of the caregivers of patients in our study was 39.15. Standard deviation of the age of caregivers in our study was 7.67. Other socio-demographic data of the caregivers is tabulated in table no.1.

Table 1- Socio – demographic profile of the caregivers

Variables	Frequency	Percentage
Age < 40 yrs (18 to 40)	61	61%
Age > 40 yrs (41 to 55)	39	39%
Males	39	39%
Females	61	61%
Low Socio-economic status	19	19%
Middle Socio-economic status	69	69%
High Socio-economic status	12	12%
Literate	70	70%
Illiterate	30	30%
Married	94	94%
Unmarried	6	6%
Employed	41	41%
Unemployed	59	59%
Total	100	100%

Table 2- Patient's duration of illness

Patient's duration of illness	Frequency (n)	Percentage
Less than 1 year	39	39%
More than 1 year	61	61%
Total	100	100%

Table 3- Burden among the caregivers

S.no	Areas of burden	Mean	SD	SE
1.	Impact on well being	6.86	1.664	0.166
2.	Impact on marital relationships	6.16	3.139	0.314
3.	Impact on relations with others	6.88	1.742	0.174
4.	Appreciation for caregiving	6.11	1.746	0.175
5.	Perceived severity of diseases	6.23	2.322	0.232
Total score of burden assessment schedule		32.06	7.523	0.752

Inferential Statistics:
Table 4- Association between diagnosis of the patient and caregiver burden

Patients Diagnosis Vs Caregiver Burden		Caregiver Burden	
		High Burden	Low Burden
Patient diagnosis	Psychosis 78%	39	11
		22%	
	Neurosis 50%	25	25
		50%	
Total		50	50
		64%	36%
chi square value (x²) = 8.507		P value= 0.004	

This indicates that there is a high caregiver burden in psychosis than neurosis.

Table 5– Association between duration of illness of the patient and caregiver burden

Patients Duration Of Illness Vs Caregiver Burden		Caregiver Burden		Total
		High Burden	Low Burden	
Patient duration of illness	less than 1 year	20	19	39
		51.3%	48.7%	100%
	more than 1 year	44	17	61
		72.1%	27.9%	100.0%
Total 64%		64	36	100
		36%	100%	
chi square value (x²) = 4.488		'p' value = 0.034*		

It clearly shows that there is a high caregiver burden in the caregivers of patients with duration of mental illness more than 1 year.

The Psychotic illnesses, have a higher impact on the wellbeing of caregivers than the Neurotic illnesses (x^2=13.5; 'p' value =.000). The caregivers wellbeing is affected significantly if the illness duration is more than 1 year (x^2=7.174; 'p' value =0.007).There was high caregiver burden on caregivers belonging to middle and lower socio economic status than the caregivers belonging to high socio economic status (x^2=11.318; 'p' value =0.03). For other independent variables of our study, there were no statistical significant associations with the impact on wellbeing of caregivers. There was also a high impact on marital relationships of caregivers of patients with psychosis than neurosis (x^2=6.895; 'p' value =0.006).Caregiver marital status had an impact on caregiver marital relationship (x^2=4.237; 'p' value =0.040). The spouse had more impact on their marital relationships than the other caregivers (x^2=4.979; 'p' value =0.026).

For other independent variables of our study, there were no statistical significant associations with the impact on marital relationships of caregivers. There was statistical significance in the association between Patient diagnosis and impact on caregiver relations with others (x^2=4.937; 'p' value =0.026).Similarly we tried finding association between the other independent variables of our study and the subscale -impact on caregivers relationships with others. But there were no significant association found between them.

The "appreciation for caring domain' scores were grouped in to high appreciation (scores 7 to 12) and low appreciation (scores≤ 6).

On analyzing by using chi square test of significance, there were no significant association found between the independent variable and the positive factor appreciation domain.

Caregivers who were employed had a higher perception of severity of the disease than the caregivers who were unemployed (x^2=4.362; 'p' value =0.037). Other than the employment status of caregivers, no other independent variable was significantly associated with the perceived severity domain of BAS.

Table 6- Summary of other statistically significant associations between independent variables and the study outcome variable

Variables	(x)²	'p' value
Diagnosis AND Impact on wellbeing	13.5	0.000
Illness duration AND Impact on wellbeing	7.17	0.007
Diagnosis AND relations	4.93	0.026
Diagnosis AND Impact on marital relationships	6.89	0.009
Caregiver relation AND Impact on marital relationships	4.97	0.026
Caregiver marital status AND Impact on marital relationships	4.23	0.040
Caregiver socioeconomic Status AND Impact on wellbeing	11.3	0.030
Caregiver occupation AND Perceived impact on diseases	4.36	0.037

Discussion:

A hospital based study among caregivers of schizophrenic patients done by Srivatsava.S et al[8] in Agra depicts that the mean burden score for impact of wellbeing was 8.43, impact on marital relationships was 10.60, and impact on relations with others was 6.36, and perceived severity of disease was 8.76.

Another community based study from Bangalore among the caregivers of patients with chronic mental illness done by Swaroop N et al,[9] a Bangalore study shows that the mean burden score for impact of wellbeing was 6.00, impact on marital relationships was 6.53, appreciation for care-giving was 6.07, impact on relations with others was 5.64 and perceived severity of disease was 5.99.

In our study the mean burden score for impact of wellbeing was 6.86(SD = 1.66) impact on marital relationships was 6.16(SD = 3.13), appreciation for care-giving was 6.11(SD = 1.74), impact on relations with others was 6.88(SD = 1.74) and perceived severity of disease was 6.23(SD = 2.32). Levels of burden in the present study were lower in all the areas when compared to the Agra study,[8]however the caregiver burden in the 5 domains is almost similar to the mean values mentioned in the Bangalore study.

In another hospital based study done in Orissa,[10] the burden among caregivers of inpatients admitted with psychiatric disorders was surveyed. Both subjective and objective burden was observed to be 53.33%. It was observed that Subjective Burden was high in younger age and female sex in that study.

Nuclear family and educational years and contrarily associated with marital and work status. We found no such significant relationship between age, sex and caregiver burden in our study.

In a study done in a Nigeria to evaluate burden among caregivers of patients with schizophrenia, the author demonstrated that the burden was higher in female caregivers.[11]

Whereas in our study, the burden was not high in female caregivers. In our study, the caregiver burden was significantly higher in patients with psychosis when compared to patients with psychosis. This finding is similar to the Bangalore study done by Swaroop N etal,[9]where they found significant association between the type of mental illness and impact on caregivers relationships with others, also between the type of mental illness and impact on caregivers marital relationships.

The higher caregiver burden seen in psychosis in our study could be explained by the illness per se and the negative social stigma of psychosis or schizophrenia.

Our study was done in a tertiary medical college hospital setting where the patients are severely ill and hence the high burden among the caregivers. Caregiver burden is very critical in relapse prevention.

Implications:

This study emphasizes the fact that the caregivers of patients with mental illness also need support, understanding on the part of the health professionals. This study aims in identifying caregiver burden at the earliest and to treat them to prevent their burnout. Caregiver burden must be taken into account when planning for intervention.

Limitations:
Hospital based study
Sample size
Heterogeneous individual psychiatric disorders were grouped into two groups of psychosis and neurosis and so the caregiver burden of individual psychiatric disorders like anxiety, depression, OCD, etc., couldn't be deduced.

Conclusion:
This study was done to quantify caregiver burden among primary caregivers of persons with mental illness. We also found associations between socio-demographic data, clinical variables and the outcome variable (burden). We conclude that there is high caregiver burden with psychosis and in patients with longer duration of mental illness (more than 1 year). Caregiver burden must be taken into account when planning for intervention in mental illness. Future studies should aim in identifying caregiver burden at the earliest and to treat them to prevent their burnout.

References:

1. Fadden G, Bebbington P, Kuipers L. Caring and its burdens. A study of the spouses of depressed patients. Br J Psychiatry1987;151:660-7.

2. Treudley MB. Mental illness and family routines. MentHyg1946;15:407-18.

3. Platt S. Measuring the burden of psychiatric illness on the family: an evaluation of some rating scales. Psychol Med 1985;15(2):383-93.

4. Grad J, Sainsbury P. Mental illness and the family. Lancet 1963;1(7280):544-7.

5. Mattoo SK, Nebhinani N, Kumar BN, Basu D, Kulhara P. Family burden with substance dependence: a study from India. Indian J Med Res 2013;137(4):704-11.

6. Pai S. &Kapur, R.L. The burden on the family of a psychiatric patient: development of an interview schedule. Br J Psychiatry 1981;138:332-5.

7. Sell H, Thara R, Padmavati R, Kumar S. The Burden Assessment Schedule (BAS). WHO Regional Publications, South-East Asia, Series No.27. New Delhi: World Health Organization, Regional Office for South-East Asia; 1998. p. 15-20.

8. Srivastava S. Perception of burden by caregivers of patients with schizophrenia. Indian J Psychiatry 2005;47(3):148-52.

9. Swaroop N, Shilpa R, Ramakrishna G, Maria A, Tony MP, Anjali P, et al. Burden among caregivers of mentally ill patients: A rural community based study. Int J Res Dev Health. April 2013;Vol:1(2). Available from: http://www.ijrdh.com/files/2%20BURDEN%20AMONG%20CAREGIVERS%20%20-final%20-.pdf

10. Holikatti P, Kar S, Shukla RK, Swain SP, Mishra A. Burden on Caregiver of Psychiatric In-Patients. Orissa Journal of Psychiatry. September 2008;16:37-46.

11. Available from: http://www.spragroup.org/orissajp.com/pdf/08/6.pdf

12. Adeosun II. Correlates of Caregiver Burden among Family Members of Patients with Schizophrenia in Lagos. Nigeria Schizophr Res Treatment 2013;2013:353809.