

BURDEN OF CARE IN CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA AND EPILEPSY

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ABSTRACT

Objectives: To find out the burden of care and associated mental health problems in caregivers of patients with schizophrenia and epilepsy.

Design: Cross sectional study.

Place and duration of study: This study was conducted at the Department of Psychiatry, Sir Ganga Raam Hospital, Lahore, from January to September 2010.

Subjects and Methods: A total of 100 caregivers (50 each) of patients suffering from schizophrenia and epilepsy presented to the outdoor patient department were included in the study. Burden Assessment Scale, General Health Questionnaire-28 and a semi structured proforma for recording their demographic details were used in the study.

Results: Forty nine percent caregivers of patients of schizophrenia and epilepsy showed high burden of care on Burden Assessment Scale. Overall, 55% of caregivers had higher scores on General Health Questionnaire showing poor psychological well being and problems with their mental health. There were highly significant positive relationship ($p < .001$) between BAS, GHQ and all their subscales i.e., objective burden, subjective burden, somatic symptoms, anxiety and insomnia, social dysfunction and severe depression.

Conclusion: Almost half of the caregivers showed high burden of care and the majority had problems with their mental health.

Key words: Caregivers, Burden of care, Burden Assessment Scale (BAS), General Health Questionnaire (GHQ), Schizophrenia, Epilepsy

INTRODUCTION

Caregivers play an important role in the management of all the chronic mental illnesses^{1,2}. They may be family members, friends or relatives of the patient³. Literature review indicates that caregivers who persistently deal with the patients of chronic mental illness show signs of stress in various forms⁴⁻⁶. Caregiving is a time-consuming responsibility, creating social, emotional, behavioral and financial problems for the caregivers and cause various limitations on their personal life^{7,8}.

Role overload may be one of the possible causes of stress due to burden of care^{9,10}. Multiple and/or chal-

lenging demands of time and resources are supposed to lead to the negative physical and psychological consequences of caregiving^{11,12}. It encompasses a wide range, from mild irritation to drastic dysfunction that may cause severe health problems^{13,14}. It may include burn out, physical exhaustion and deterioration of mental and physical health^{15,16}. Limitation of one's social life is Most commonly cited constrain among caregivers of moderately and severely impaired persons is the undue limitation on the social activities of life¹⁷.

Caregivers within the family have often been described as forgotten patients and it was suggested that caregivers' symptoms such as mood swing, fatigue, headaches, joint and muscle pains, marital and family conflicts and financial problems may have been a reflection of caregivers' stress in looking after a sick relative^{18,19}. Researches exploring burden and emotional distress in caregivers have enumerated various problems ranging from stigma to financial difficulties without any public assistance and suggested these to be arising from providing care to a sick relative^{20,21}.

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Studies have been carried out to investigate the etiology, epidemiology and treatment patterns of the psychiatric disorders with most of them focusing on the patients. There has been less attention on the issues of the caregivers who take care of the patient and clinicians hardly give any attention to their needs. Therefore, this study was planned to find out the burden of care and associated mental health problems in caregivers of patients with schizophrenia and epilepsy.

SUBJECTS AND METHODS

This study was conducted at the Department of Psychiatry, Sir Ganga Raam Hospital, Lahore, from January to September 2010 after the approval of research proposal from Ethical Review Board (ERB) of Sir Ganga Ram Hospital, Lahore. A total of 100 caregivers (50 each) of patients suffering from schizophrenia and epilepsy presented to the outdoor patient department were included in the study through convenience sampling after taking their written informed consent. The confidentiality and anonymity was ensured. The care receivers were already diagnosed as patients suffering from schizophrenia and epilepsy on the basis of ICD 10 criteria²².

Participant's age, gender, education level, socio-economic status, family system and marital status were recorded on a semi structured proforma. Two standardized scales were then administered;

Burden Assessment Scale (BAS)²³ is a 5-point Likert type scale where 1 = not at all and 5 = not applicable. The Urdu translated version was used which consists of 19 items with the distribution of 1-10 objective and rest of 9 items of subjective burden. There median of scores was used as a cut-off point between high and low burden which in this case was 71.

General Health Questionnaire (GHQ) - 28²⁴⁻²⁶ is a 28 items scale to identify psychiatric disorders among respondents in community and non psychiatric clinical settings. The 28 items are distributed in 4 subscales of somatic symptoms; anxiety and insomnia; social dysfunction; and severe depression. Responses to each item are scored as 0-3, where 0 = not at all and 3 = much more than usual.

Statistical Package for Social Sciences (SPSS) v.16 was used for the statistical analysis of the study

RESULTS

The mean age of the sample was 38.78+ 13.10. Most were women (n=60), married (n=94), school educated (n=46), unemployed/ housewife (n=58), in lower socioeconomic class (n=71), in nuclear family (n=68) and living in urban area (n=67). The detailed demographic characteristics are shown in Table 1.

The results indicate that 49% of caregivers were having high burden of care while equal number of caregivers (n=50) were having low and high objective and subjective burden on Burden Assessment Scale

Table 1: Demographic Characteristics of the sample (n= 100)

Variables	Number of patients
Age	
>30	26
31-40	46
<40	28
Gender	
Women	60
Men	40
Marital status	
Married	94
Unmarried/Separated/Widow	06
Education	
Illiterate	40
School	46
College/University	14
Occupation	
Unemployed/House wife	58
Employed	42
Socio economic status	
Lower	71
Middle	29
High	0
Family System	
Nuclear	68
Joint	32
Area	
Urban	67
Rural	33

with cut off of 38.5 and 33.5 respectively. The results on General Health Questionnaire showed that 55% caregivers were suffering from over all psychiatric problems. Out of 100, 56% caregivers suffered from anxiety and insomnia, 53% from social dysfunction, 52% somatic symptoms and 48% suffered from severe depression (Table 2).

There is non significant mean difference in burden of care in caregivers of schizophrenia and epilepsy while there is a significant mean difference in their mental health problems (.716) as in caregivers of epilepsy patients, it is 40.92+12.59 as compared to caregivers of patients of schizophrenia where it is 38.72+17.72 (Table 3).

Table 4 indicates the inter correlation between the variables of the study. It is evident that highly significant relationship ($p < .001$) was found among BAS, GHQ and all their subscales i.e., objective burden, subjective burden, somatic symptoms, anxiety & insomnia, social

Table 2: Details of scores on BAS and GHQ-28

Scale	Sub Scale	Low	Median (Cut off)	High
Burden Assessment Scale		51	71	49
	Objective Burden	50	38.5	50
	Subjective Burden	50	33.5	50
General Health Questionnaire		45	40	55
	Somatic Symptoms	48	13	52
	Anxiety and Insomnia	44	11	56
	Social Dysfunction	47	9	53
	Severe Depression	52	6	48

NB: For GHQ, the higher the score the poorer the psychological well-being of the patient

Table 3: Means, SD, and p-value of scores on BAS and GHQ (n=100)

	M	SD	p value
BAS			
Epilepsy	66.16	15.14	0.454
Schizophrenia	70.30	14.48	
GHQ			
Epilepsy	40.92	12.59	016*
Schizophrenia	38.72	17.72	

df = 98, *p value = < .05.

dysfunction and severe depression. Gender had highly significant ($p < .001$) correlation with subjective burden, GHQ, somatic symptoms and anxiety and insomnia; Occupation had a strong inverse relation with BAS, subjective burden, and somatic symptoms; Education and socioeconomic status had inverse correlations with BAS, subjective burden, objective burden, GHQ, somatic symptoms and social dysfunction; Family system had inverse correlations with GHQ, somatic symptoms, anxiety and insomnia and social dysfunction; while area of living had a positive correlation with GHQ and anxiety and insomnia and negative correlation with social dysfunction, respectively.

Table 4: Pearson correlation of the variables (n=100)

	2	3	4	5	6	7	8	9	10	11	12	13	14
1. BAS	.90**	.93**	.51**	.50**	.45**	.45**	.28**	.21*	-.27**	-.28**	-.35**	-.12	.01
2. Subjective burden		.68**	.49**	.50**	.45**	.39**	.24**	.28**	-.35**	-.28**	-.31**	-.11	.01
3. Objective burden			.46**	.43**	.39**	.42**	.27**	.12	-.15	-.23*	-.33**	-.12	.00
4. GHQ				.84**	.85**	.79**	.46**	.26**	-.20	-.20*	-.15	-.23*	-.25*
5. Somatic Symptoms					.75**	.50**	.44**	.35**	-.30**	-.21*	-.22*	-.22*	-.20
6. Anxiety & Insomnia						.57**	.45**	.21**	-.17	-.13	-.18	-.16**	-.29*
7. Social dysfunction							.57**	.11	-.07	-.21*	-.21*	-.20*	-.20*
8. Severe Depression								.15	-.07	-.10	.08	-.18	-.13
9. Gender									-.88**	-.25*	-.11	-.14	.08
10. Occupation										.32**	.13	.07	-.09
11. Education											.31**	.17	.01
12. Socioecon. Status												.22*	.07
13. Family system													-.07
14. Area of Living													

*p < .05, **p < .001

DISCUSSION

Results of the study indicate that burden of care and mental health problems are high in caregivers of patients with schizophrenia and epilepsy and this is consistent with the findings of other studies^{27,28}.

The findings of our study also show that mental health of caregivers remains on stake when they have high level of burden of care, regardless of the fact that schizophrenia and epilepsy are different disorders in nature. Similar findings have been reported in the previous studies showing that chronic mental illnesses generally affect the overall functioning of caregivers and bring negative consequences on their mental health^{29,30}. According to the social model scarcity of the means, unequal distribution of the resources, lack of the responsibility, unawareness of the problems, ignorance, uncertainty, psychosocial and environmental stressors and poverty are some of the potential reasons for it²⁸.

As reported in the previous studies, chronic mental illnesses generally affect the overall functioning of caregivers and bring specific severe consequences on mental health and one out of four American workers suffer a mental health problems rooted in stress related problems³¹.

Results indicate that there were significant relationship among BAS, GHQ, their subscales and other demographic variables such as socio-economic status, education, marital status, area of living etc. and these variables were significant contributors on burden of care. These findings are consistent with the study of Sheehan and Nuttall³².

Keeping in view the wide implications of present research, it is suggested that clinicians, psychiatrist, psychologists, therapists and other health workers not only provide assistance to the patients but also give proper attention to the caregivers.

CONCLUSION

Almost half of the caregivers showed high burden of care and the majority had problems with their mental health. There was highly significant relationship among BAS, GHQ and all their subscales i.e., objective burden, subjective burden, somatic symptoms, anxiety and insomnia, social dysfunction and severe depression.

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