

Caregiver burden and coping strategies in schizophrenia: a hospital based study

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Abstract

Introduction: Schizophrenia is a severe mental illness which not only affects the patients but also causes significant distress to the caregivers, who use various strategies to minimize their distress. It is important to know about their suffering in order to include them in the treatment program.

Objective: To assess the severity of burden and coping strategies among the caregivers

Method: 36 admitted cases of patients and their caregivers were enrolled. Patients were assessed using PANSS while caregivers were assessed using BAS and COPE Inventory.

Result: 47.2% caregivers reported suffering from severe burden. The most severely affected areas were physical and mental health, taking responsibility, caregiver's routine and patient's behavior. Caregivers used both problem oriented and emotion oriented strategy to minimize the distress. The choice of coping strategy and severity of burden was not influenced by the patient's symptoms.

Conclusion: Caregivers of patients with schizophrenia suffered from significant burden and require additional care to help them alleviate their problems.

Keywords: Schizophrenia, Burden, Coping

INTRODUCTION

Schizophrenia is a severe mental disorder affecting 21 million people worldwide. It is characterized by distortions in thinking, perceptions, emotions, language, sense of self and behaviour.¹ The resulting disability can have a considerable impact on the caregivers' daily lives, physical health and emotional well being.²

The term burden has been described as "the consequences for those in close contact with severely ill psychiatric patients".³ It has been classified into subjective and objective dimensions. Subjective burden refers to the psychological consequences of the individuals' illness on the family such as distress. Objective burden refers to the disruption in family or household and is usually observable such as household routines, relationships.⁴ However,

some authors consider the term burden as derogatory and a more appropriate term is considered to be "caregiving".⁵

The impact of schizophrenia on their caregivers has been a focus of considerable interest and a number of studies have shown that caregivers regularly suffer from various problems such as disruption of routines, relation problems, financial loss and emotional distress.⁶⁻¹¹ In response to these problems, caregivers employ a variety of coping strategies which include approach strategies such as seeking support and education, positive reframing and problem solving as well as avoidant strategies such as denial and disengagement.¹²

Some studies have studied burden and coping in relation to patients' symptoms. While some found that burden and coping are influenced by

positive symptoms^{13,14} others have concluded that negative symptoms are more helpful predictors of burden and coping strategies.^{15,16} Still others did not find any difference between the two domains of symptoms.^{4,17}

In a country like Nepal, caregivers have to deal with the major brunt of patients' illness and this not only affects the caregivers' physical and mental health but also has adverse consequences for patients whose needs are frequently unmet due to decreased functionality of the caregivers.¹⁸ As stated by Rosenfarb et al (2006) cultural factors play an important role in determining the degree to which patients are experienced as burdensome.¹⁹ Hence this study was undertaken to assess the severity of burden and coping strategies among the caregivers and it's relation to patients' symptoms in context of Nepal.

MATERIAL AND METHOD

This is a descriptive and cross sectional study conducted among caregivers of patients with schizophrenia admitted in the psychiatry ward of BPKIHS. Patients and caregivers of all the patients admitted during a period of one year (January 2013 to December 2013) (N=36) were enrolled after obtaining informed consent. A semi-structured pro-forma was used to obtain information about the socio-demographic characters of the patients and caregivers. Patients were assessed using the Positive And Negative Syndrome Scale (PANSS) while the caregivers were assessed using the Burden Assessment Schedule (BAS) and the COPE Inventory. BAS and COPE Inventory were in English language and therefore, translation and back translation was done to obtain a Nepali language scale.

PANSS was developed by Kay et al in 1987 for the assessment of positive and negative symptoms in schizophrenia. It consists of 30 items in three subscales, positive symptoms, negative symptoms and general psychopathology. Each item is rated on a seven point scale which represents increasing levels of severity. The alpha coefficient for the three subscales are 0.73, 0.83 and 0.79 respectively. The PANSS score is summation of ratings across items, so the potential ranges are 7-49 for the positive and negative scales, 16-112 for the

general psychopathology scale and -42 to +42 for the composite scale.²⁰

BAS was developed by Thara et al (1998). This is a 40 item scale measuring seven different areas of burden. Each item is rated on a 3 point scale. Internal consistency for the full scale as measured by the alpha coefficient is 0.81. Criterion validity was established by comparing the instrument with the family burden schedule (Pai and Kapur,1981). Correlations for most of the items was found to be good and ranged between 0.71-0.82.²¹

The COPE Inventory was developed by Carver et al (1989). It consists of 14 scales with each scale containing 4 items except for 1 (53 total). Each item is rated on a 1-4 scale so the total score for each item is 4-16. 5 of the scales measure problem based strategies. 5 others measure emotion based strategies while the rest measure coping responses that arguably are less useful.²²

The collected data was entered in Microsoft-Excel 2007 and converted into SPSS 16.0 for statistical analysis. Descriptive statistics were analysed using mean, standard deviation, number and percentage while for inferential statistics chi square and pearson correlation was used.

RESULT

The mean age of patients was found to be 31.2 ± 7.43 years while that of the caregivers was 42.8 ± 14.8 years. 29(80.6%) patients were male while 7(19.4%) were female. Majority of the patients were Hindu, educated upto SLC, unemployed and unmarried. Similarly, 52.8% of the caregivers were male and the majority of caregivers were illiterate, married and farmer. 11(30.6%) of the caregivers were siblings of the patients while 8(22.2%) and 7(19.4%) were fathers and mothers respectively. (Table 1)

The assessment of patients using PANSS showed that the mean total score was 90 ± 14.3 SD. The mean score was highest for the general psychopathology subscale followed by negative subscale with the positive subscale having the lowest mean score (Table 2).

The mean burden score at the time of admission was 81.3 with a standard deviation of 15.9. The total burden score ranged from as less as 51 to as high as 106. 19(52.8%) caregivers reported

Table no. 1: Socio-demographic Profile Of Patients and Care-Givers

Variable		Patients	Caregivers
Mean Age ± SD (years)		31.2 ± 7.43	42.8 ± 14.8
Age distribution No. (%)	18-30	24(66.7)	11(30.6)
	31-40	8(22.2)	7(19.4)
	41-50	3(8.3)	7(19.4)
	51-60	1(2.8)	6(16.7)
	Above 60	0(0)	5(13.9)
Total		36(100.0)	36(100.0)
Gender No. (%)	Male	29(80.6)	19(52.8)
	Female	7(19.4)	17(47.2)
Total		36(100.0)	36(100.0)
Religion No. (%)	Hindu	30(80.3)	30(80.3)
	Buddhist	1(2.8)	1(2.8)
	Christian	1(2.8)	1(2.8)
	Others (Kirat)	4(11.1)	4(11.1)
Total		36(100.0)	36(100.0)
Education No. (%)	Illiterate	0(0)	12(33.3)
	Primary	4(11.1)	3(8.3)
	Middle	5(13.9)	6(16.7)
	SLC	14(38.9)	5(13.9)
	Intermediate	9(25.0)	4(11.1)
	Graduate	4(11.1)	6(16.7)
Total		36(100.0)	36(100.0)
Occupation No. (%)	Business	2(5.6)	2(5.6)
	Farmer	4(11.1)	13(36.1)
	Labourer	7(19.4)	4(11.1)
	Service	3(8.3)	5(13.9)
	Housewife	1(2.8)	7(19.4)
	Student	5(13.1)	2(5.6)
	Unemployed	13(36.1)	3(8.3)
	Others	1(2.8)	0(0)
Total		36(100.0)	36(100.0)
Marital status No. (%)	Bachelor	18(50.0)	7(19.4)
	Married	16(44.4)	29(80.6)
	Single	2(5.6)	0(0)
Total		36(100.0)	36(100.0)
Relation to patient No. (%)	Father	-	8(22.2)
	Mother	-	7(19.4)
	Spouse	-	9(25.0)
	Sibling	-	11(30.6)
	Other (Uncle)	-	1(2.8)
Total		-	36(100.0)

Table no. 2: Showing PANSS Score during Admission

PANSS	Mean	SD
Total	90.1	14.3
Positive subscale	25.0	11.0
Negative subscale	26.4	11.2
General psychopathology	38.5	7.7

Table no. 3: Distribution of caregiver sample in various domains of burden

BAS	Assessment of severity	Number	Percentage	P value
Total burden	None	0	0	0.74
	To some extent	19	52.8	
	Very much	17	47.2	
Spouse related	None	0	0	0.73
	To some extent	4	44.4	
	Very much	5	55.6	
Physical and mental health	None	0	0	0.02
	To some extent	11	30.6	
	Very much	25	69.4	
External support	None	0	0	<0.001
	To some extent	30	83.3	
	Very much	6	16.7	
Caregiver's routine	None	1	2.8	<0.001
	To some extent	12	33.3	
	Very much	23	63.9	
Support of patient	None	1	2.8	0.001
	To some extent	17	47.2	
	Very much	18	50.0	
Taking responsibility	None	0	0	0.02
	To some extent	11	30.6	
	Very much	25	69.4	
Other relations	None	3	8.3	0.004
	To some extent	14	38.9	
	Very much	19	52.8	
Patient's behaviour	None	0	0	0.04
	To some extent	12	33.3	
	Very much	24	66.7	
Caregiver's strategy	None	0	0	0.50
	To some extent	16	44.4	
	Very much	20	55.6	

burden "to some extent" while 17(47.2%) were experiencing severe burden. The difference was not significant indicating that caregivers were equally likely to experience either moderate or severe burden. However, except for the spouse

related and the caregiver strategy domains, the difference in the proportion of caregivers experiencing moderate and severe burden was found to be significant for the rest. The most severely affected areas were physical and mental health and taking responsibility where 25(69.4%) caregivers reported as suffering from severe burden. The least severely affected domain was external support where 6(16.7%) reported as suffering from severe burden. (Table 3)

Table no. 4: Distribution of the caregiver sample according to the coping strategy maximum used

Coping strategy	Number	Percentage	P value
Active coping	10	27.8	0.737
Planning	13	36.1	
Suppression of competing activities	13	36.1	
Restraint coping	11	30.6	
Seeking social support for instrumental reasons	17	47.2	
Seeking social support for emotional reasons	16	44.4	
Positive interpretation and growth	9	25.0	
Acceptance	11	30.6	
Turning to religion	16	44.4	
Focus on and venting of emotions	11	30.6	
Denial	0	0	
Behavioural disengagement	5	13.9	
Mental disengagement	1	2.8	
Alcohol-drug disengagement	0	0	

Assessment of coping strategies revealed that the most common coping strategy used by the caregivers at the time of admission was seeking social support for instrumental reasons with 17(47.2%) caregivers reporting maximum use of this strategy. This was followed by turning to religion and seeking social support for emotional reasons with 16(44.4%) caregivers

reporting maximum use of both these strategies (Table 4). An overall analysis of only those strategies which have been clearly categorized as either problem oriented or emotion oriented in the COPE Inventory²² did not reveal any significant difference. This shows that the caregivers used both types of strategies equally. The mean scores were highest for turning to religion and seeking social support for instrumental reasons with $11.6 \pm 3.2SD$ and $11.1 \pm 4.2SD$ respectively. (Table 5)

The small positive correlation between different subscales of PANSS and BAS was not found to be significant. Similarly, the choice of coping was also not found to be influenced by patients' symptoms. (Table 6)

Table no. 5: Mean Scores of COPE Inventory

Coping strategy	Mean score	SD
Active coping	9.5	3.6
Planning	10.2	4.4
Suppression of competing activities	10.3	3.8
Restraint coping	9.9	4.3
Seeking social support for instrumental reasons	11.1	4.2
Seeking social support for emotional reasons	11.0	4.1
Positive reinterpretation and growth	8.4	4.2
Acceptance	10.1	4.3
Turning to religion	11.6	3.2
Focus on and venting of emotions	10.6	3.7
Denial	4.9	1.9
Behavioural disengagement	7.4	4.2
Mental disengagement	6.9	2.5
Alcohol-drug disengagement	1.1	0.5

Table no. 5: Correlation between severity of symptoms, caregiver burden and coping strategies

PANSS	BAS		COPE Inventory	
	r value	p value	r value	p value
Total	0.211	0.218	0.111	0.52
Positive subscale	0.060	0.728	0.140	0.416
Negative subscale	0.127	0.460	- 0.90	0.602
General psychopathology	0.121	0.480	0.188	0.272

DISCUSSION:

The fact that caregivers of patients with schizophrenia suffer from significant burden has been shown in several studies.⁶⁻¹¹ This study shows that the caregivers in Nepal are no different with 47.2% reporting severe burden. The mean score of 81.3 ± 15.9 indicating severe burden is similar to the findings of Rammohan et al (2002)²³. The major areas were physical and mental health, taking responsibility, patient's behavior and caregiver's routine. Feeling depressed and anxious and having financial difficulties have also been reported as the major area of burden in other studies.²⁴ The finding that external support was the least affected domain is in contrast to the findings of Vasudeva et al (2013).²⁵ The less severe burden in our study could be because of fewer female spouses in our study. As reported by Kumar and Mohanty (2007)²⁶ female spouses of patients with schizophrenia often use projection as a defense mechanism which increases the interpersonal conflict resulting in greater difficulty in getting external support.

Whenever we encounter any event, through processes of primary and secondary appraisal we try to evaluate if the event is harmful and if it is, what can be done to prevent the harm. Accordingly we change our cognitive and behavior efforts. Caregivers in schizophrenia also use various strategies to overcome their distress. These strategies can be either adaptive or maladaptive. This study shows that they tend to use both problem oriented and emotion oriented strategies equally. Seeking social support has been shown to be an important strategy in other studies as well.^{10,11} Another important strategy in our study was turning to religion. This finding reflects the lower education level of the caregivers. As reported by Magliano et al (1998) caregivers with lower education level more frequently use seeking spiritual help as a coping strategy.²⁷ The finding that caregivers used all strategies equally further emphasizes the need for proper psychoeducation of the caregivers.

A major limitation of our study is the limited sample size. As this study was done among caregivers of patients requiring admission, some may argue that it has overestimated the burden

experienced by the caregivers. However, our study has failed to show any relation between the severity of symptoms and the burden experienced or choice of coping strategy. The relation between symptoms, burden and coping is not clear in literature. Further studies involving more number of patients from various settings are required to verify this finding.

CONCLUSION:

Caregivers are often the silent sufferers who not only have to deal with the patient's illness but the additional problems of their own. In view of these findings it is important to include them early in the treatment process and address their problems as well.

ACKNOWLEDGEMENTS:

The authors would like to thank all the patients and their caregivers who participated in the study and also the entire department of psychiatry, BPKIHS.

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