

Burden and Coping Methods among Care Givers of Patients with Chronic Mental Illness (Schizophrenia & Bpad)

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I. Introduction

The care givers of patient's with Schizophrenia and Bipolar disorders experience considerable burden while caring for their patients. They have to develop different coping strategies to deal with this burden.

Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person with some kind of illness. A person caring for someone with a chronic illness may experience stress in the form of financial strain, management of person's symptoms, dealing with crisis, the loss of intimacy (Tull, 2008).

Perlick&Rosenheck (2007) in New York studied 500 caregivers of adults with schizophrenia to identify the caregivers at risk and with poor health in relation to care giving and stress. The caregivers comprised 3 groups: burdened, effective, and stigmatized. High burden care givers reported more physical health problems, depressive symptoms, health risk behaviour, health service use, and less social support than less burden care givers.

Gangly&Chadda (2010) conducted a longitudinal study of burden and coping in a group of care givers of people suffering from schizophrenia and bipolar affective disorder. They reported that the caregivers of people with mental disorders suffer from having a considerable burden as a result of their care giving role and they expressed burden in different areas such as family functioning, non-acceptance by society and socialisation, financial problems and health.

Compared to non-caregivers, caregivers often experience psychological, behavioural, and physiological effects that can contribute to impaired immune system function and coronary heart disease, and early death. The care givers develop different kinds of coping strategies to deal with the burden including developing compassion in care giving, hoping for a better future, developing faith in God, participating in religious practices, and helping others with similar problem (Gouin JP, Hantsoo 2008).

Professional caregivers such as physicians and nurses, informal caregivers, family members or friends, provide care to individuals with a variety of conditions including advanced age, chronic illnesses, mental illness; naturally they perceive chronic stress that leads to burden. They often experience negative psychological, behavioural and physiological effects on their daily lives and health. Family medicine Physicians are dealing with primary care givers who provide care for chronically ill, mentally ill patients and have opportunity to intervene. Moreover they can assess the health status and assess their associated burden and identifying at risk of negative health outcomes and intervening to attenuate the stress associated with the care givingburden (NAC).

Physicians do not commonly query the caregiver regarding concerns they have about providing care. Caregivers become "the invisible patient" and often have significant health and psychosocial needs that, in turn, affect caregiving. Silliman RA (1989)SchoenmakersB, Bunting F (2009).

Most family caregivers are untrained and often feel ill prepared to take on care giving tasks. This is especially true for caregivers who provide more medically skilled care giving such as changing catheter bags, providing wound care, or overseeing complex medication management. Caregivers who are the primary interface with the health care system often receive inadequate support from health professionals and frequently feel abandoned and unrecognized by the health care system.(Lilly MB, Robinson CA 2012).

The direct responsibilities of a caregiver including: assisting with activities of daily living, administering medications, providing transportation, preparing meals, managing finances, advocating for health care, and providing emotional support. As a result, caregivers experience layer upon layer of stress, as the burden of caring for their sick loved ones, separated from their own support systems, while balancing other life responsibilities, threatens to overwhelm them.

Hypothesis:

H1: There is a significant relationship between burden and selected demographic and clinical variables.

H2: There is a significant relationship between coping and selected demographic and clinical variables.

Aim of the study:

Aim of the study was to assess the burden and coping strategies employed by care givers of patients having schizophrenia or BPAD and their relationship with sociodemographic variables.

Need for the study: Interactions with caregivers of patients with severe mental illness like schizophrenia and bipolar affective disorder have revealed negative feelings about the disability status of their relative and burden related to caring for their relative with mental illness. Many caregivers have expressed that the patient's disability status affects the family pattern, roles of family members, prosperity of the family and relationship among the family members.

^Patient outcome and compliance with treatment are also dependent on optimal caregiving and addressing family's needs. Unfortunately these needs are not routinely considered, addressed or met. Addressing the burden perceived by caregiver and improving their coping can assist with good clinical care of patients with severe mental illness and hence this study to assess the burden perceived by caregiver and their coping.

Methodology

Research design: Cross sectional study design was used for the study.

Setting of the study: This study was carried out in the Department of Psychiatry, CMC, Vellore which caters to patients with severe and minor mental disorders. Assessments were carried out among primary caregivers of outpatients and inpatients attending the hospital.

Population: Family member who is the primary caregiver of patients with schizophrenia or bipolar affective disorder who attended the outpatient department or were admitted to the inpatient facility of the department were approached for suitability of inclusion in the study. They were recruited after obtaining the informed consent.

Sample: A total of 130 primary caregivers, 65 of them caring for patients with schizophrenia and 65 caregivers of patients with bipolar affective disorder and consented to participate in the study were included in the study.

Sampling technique: Caregivers of consecutive patients attending the hospital or admitted to the ward were recruited.

Description of the instruments

Part i: Socio demographic variables of the primary care giver

Part ii: BURDEN ASSESSMENT SCALE (BAS) was developed by (Thara et al, 1998) comprised of 40 items. It is a structured instrument to measure caregiver burden, which has been standardized in Indian population. The items are rated on a 3 point scale, marked 1-3 with responses being not at all, to some extent, and very much.

The instrument has been reported to have a good inter-rater reliability value between the interviewers was good (Kappa, 0.80) and satisfactory face validity in terms of the relevance of the items in measuring caregiver burden.

PART III: —MODIFIED JALOWIEC COPING SCALE (JCS) was developed by Jalowiec in 1977 and was revised in 1987 and in 2003. It was used to assess general coping strategies and to find out the relationship of coping with burden. This 22 item questionnaire is based on Lazarus model of coping and helps to assess a wide range of coping behaviours. The revised JCS has 60 items classified into 8 coping methods. Jalowiec has comprehensively evaluated the construct validity of the JCS and has reported adequate internal consistency for the three factors (cronbach's alpha 0.70-0.85); Jalowiec, Murphy & Power's, 1984.

Data analysis:

Descriptive statistics were carried out for the sample. Independent 't' test, Pearson's co-relation co-efficient, Chi-square and logistic regression were used to find the association between socio demographic variables with burden and coping.

Results

Table 1: Description of primary care givers according to the socio-demographic variables.

Variables	Schizophrenia		BPAD	
	n	%	n	%
Age of the relative				
19-30	7	10.8	8	12.3
31-48	21	32.3	27	41.5
49-60	22	33.8	13	20.0
>60	15	23.1	17	26.2
Sex				
Male	30	46.2	27	41.5
Female	35	53.8	38	58.5

Educational status				
Illiterate	1	1.5	3	4.6
Primary	25	38.5	28	43.1
Secondary	26	40.0	20	30.8
Higher secondary	5	7.7	7	10.8
Graduate	8	12.3	7	10.8
Occupation				
Unemployed	24	36.9	23	35.4
Skilled	6	9.2	9	13.8
Unskilled	31	47.7	32	49.2
Professional	4	6.2	1	1.5
Income				
<1000	30	46.2	29	44.6
1001-5000	31	47.7	21	32.3
>5000	4	6.2	15	23.1
Number of living with Patient				
0-2	6	9.2	12	18.5
3-5	45	69.2	45	69.2
5-10	14	21.5	8	12.3

Table 1 shows that the majority of the caregivers belonged to the age group of 31-48yrs. Majority of them were females, married, spouse of the patient and had primary or secondary education. 98.5% of the primary care givers had been staying with the patients for more than 24 months in both the groups.

Table 2: Comparison of Mean Family burden and coping between schizophrenia and bipolar affective disorder:

Group		Mean	SD	t	df	P value
Burden	Schizophrenia	95.4769	11.51	1.552	128	0.123
	BPAD	92.2000	12.54			
Coping	Schizophrenia	62.9846	6.360	.553	128	0.581
	BPAD	62.3538	6.646			

Table 2 shows that there is no significant difference in burden and coping strategies of family members of schizophrenia and bipolar affective disorder group.

Figure 1: Distribution of care giver burden according to gender

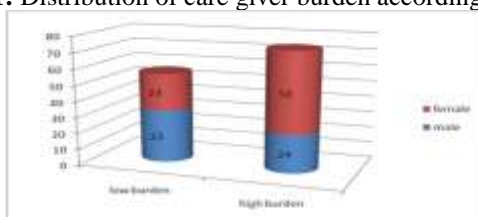


Figure 1 shows that there was a significant relationship between the gender of the care giver and the high burden, majority of those who perceived high burden were women (p=0.003).

Figure 2: Distribution of care giver burden according to their family income

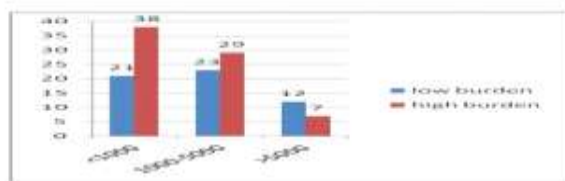


Figure 2: Distribution of care givers burden according to their family income.

Figure 2 shows that those with higher income of the family had lower levels of burden.

Figure 3: Distribution of care giver coping according to their education

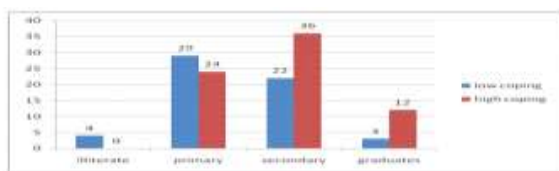


Figure 3: Distribution of relative coping according to their education.

Figure 3 shows that there was significant relationship between high level of coping strategies and high educational level of the primary care giver (p=0.011).

Table 3: Burden in caregivers according to gender and relationship to the patient.

Variable	OR	CI	P.value	
Gender	Male	1	95	
	Female	2.44	1.12, 5.29	0.003*
Relationship	Parents	3.109	1.105, 8.747	0.015*
	Spouse	1.069	0.339, 3.370	0.032*
	Other relatives	1	-	-

The multivariate risk factor analysis revealed that females have 2.44 times higher risk for developing higher level of burden when compared with men (OR 2.44; 95% CI 1.12 to 5.29; p value of 0.003).

The univariate (unadjusted) analysis reveals that parents have 3.11 times higher risk for developing higher levels of burden when compared with other relatives (OR 3.109; 95% CI 1.105-8.747; p value of 0.015) whereas spouse has the risk of 1.07 times higher risk (OR 1.069; 95% CI 0.339-3.370; p value of 0.032)

Table 4: Education and total number relatives living with the patient and coping strategies among caregivers

Variable	OR	CI	P.value	
Education of the relatives	Illiterate/primary	1	-	
	Secondary/graduate	2.640	1.292, 5.392	0.008*
Total number of relatives living with the patient	0-2	1	-	
	3-5	3.455	1.18, 10.06	0.023*
	6-10	1.385	0.37, 5.066	0.623

Table 4 reveals that the care givers who studied up to secondary level and above have 2.640 times better coping when compared to illiterates, which is statistically significant (OR 2.64; 95%CI 1.29-5.39; p value=0.008). Analysis for total number of people living with the patient reveals that family consisting of 3-5 members have got 3.46 time better coping than small/ large families which is statistically significant (OR 3.45; 95% CI 1.18-10.06; p.value=0.023).

Discussion

In this group of caregivers there was no significant difference in the burden perceived between the two diagnostic groups of patients, schizophrenia and bipolar affective disorder. This finding is similar to the report by Nehra et al., (2005). This earlier study also revealed that the pattern of burden was almost similar in both the diagnostic groups. Burden was principally felt in the areas of family routine, family leisure, family interaction and finances.

The total scores on coping strategies were also not different between caregivers of those with schizophrenia and those with bipolar affective disorder. This finding is similar to the one by Subho C et al (2002), where coping patterns of caregivers of patients with these two groups of diagnosis were quite alike though caregivers of patients with schizophrenia were using some emotion focused strategies more often. Coping and other elements of the care giving experiences in bipolar affective disorder are no different from schizophrenia.

The present study shows that there is a tendency for inverse relationship between the care giver burden and the care giver coping, (as the burden increases the coping decreases). The findings has also been reported

earlier by Talwar&Tresa (2010). Problem-focused coping strategies were more common in care givers of bipolar patients and emotion –focused strategies in caregivers of schizophrenic patients. Reducing burden on caregivers and enhancing their awareness of illness could lead to adoption of more adaptive coping styles by them.

Conclusion

Caregivers play an essential role in supporting the well-being of patients with major mental illness. In the developing world the care of the mentally ill is carried out by the family with minimal assistance from the health care system. Level of burden perceived by the primary care giver and their effective coping are factors which can have major impact on their ability to care for the patient. Future direction in the care of those with chronic mental illness should also include physician's greater role in identifying factors that may be cause distress ie, physical demands, the psychological effect of providing care, conflicts between the care recipient and others in the family, financial stresses, and behavioural issues of the care recipient that make care giving stressful (Aldrich N.2014).

Assessment and adequate support of the caregiver need to be addressed by the treating team. They should engage family caregivers as proactive partners in care, be aware of caregiver burden, and intervene in a timely manner to help reduce the burden of caregiving.

Reference

- [1]. Tull, M. (2008). Exploring the Association between emotional abuse and childhood borderline personality features: The moderating role of personality traits. *Behaviour Therapy*.
- [2]. Perlick, D. A. et al. (2007). Prevalence and correlates of burden among caregivers of patients with bipolar disorder enrolled in the Systematic Treatment Enhancement Program for Bipolar Disorder. *Bipolar Disorders*, 9(5), 262-73.
- [3]. Ganguly, K.K., &Chadda, R.K.(2009). A Study of Socio Cultural Perspectives of Care Givers in Burden Coping Behaviour in Bipolar Disorder and Schizophrenia Cases .the international *Journal of Psychosocial Rehabilitation*. Vol 13(2).93-103.
- [4]. Gouin JP, Hantsoo L, Kiecolt-Glaser JK. Immune dysregulation and chronic stress among older adults: a review. *Neuroimmunomodulation*. 2008; 15(4–6):251–259.
- [5]. NAC: Care giving in the US 2009 full report.
- [6]. Silliman RA. Caring for the frail older patient: the doctor-patient-family caregiver relationship. *J Gen Intern Med*. 1989; 4(3):237-241.
- [7]. Lilly MB, Robinson CA, Holtzman S, Bottorff JL. Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada.*HealthSoc Care Community*. 2012; 20(1):103-112.
- [8]. Aldrich N. CDC seeks to protect health of family caregivers. February 19, 2014.
- [9]. Thara R, Padmavati R, Kumar S, et al. (1998) Burden assessment schedule: instrument to assess burden on caregivers of chronic mentally ill. *Indian J Psychiatry* 40:21–2
- [10]. Jalowiec, A.(2003). The Jalowiec Coping Scale. In C.F. Waltz, L.S. Jenkins.,& O.L Strickland, *Measurement of nursing outcomes: self Care and coping*. 2.71-87
- [11]. Chakrabarti ,S.,& Gill ,S.(2002). Coping and its correlates among caregivers of patients with bipolar disorder: a preliminary study. *Bipolar Disorders* 4:50–60.