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Original Article

Burden on caregivers in Bipolar Affective Disorder and Alcohol

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ABSTRACT

BACKGROUND: Bipolar affective disorder and Alcohol dependence are two common psychiatric disorders. There are few studies on burden in caregivers of BPAD patients which have recorded significant burden. Burden on caregivers in Alcohol dependence patients has not received attention in research so far. Aim: To measure and compare the burden on caregivers of patients having BPAD and ADS. Methods: Consecutive patients aged between 18-60 yrs, having BPAD -30 patients and ADS- 33 patients were taken. After eliciting the sociodemographic data, burden was assessed using Burden Assessment Schedule (BAS) and severity of Alcohol dependence was measured by Short Alcohol Dependence Data (SADD) Questionnaire. Results: Caregivers of BPAD and ADS experienced significant burden and there was no significant difference between BPAD and ADS group. In BPAD patients burden experienced during the episode was significantly more during the episode than one month before the episode. Burden was more in severe alcohol dependent patients than in mild and moderate dependent patients. Conclusions : There was no difference in the burden experienced by the caregivers in BPAD and ADS. Burden is not limited to only severe mental disorders like psychosis, but is also seen in mental disorders like Alcohol Dependence Syndrome.

1. Introduction

Mental and Behavioural disorder are common, affecting more than 25 % of all people at sometime during their lives. These are present at any point of time in about 10% of adult population. One in four families is likely to have at least one member with mental or behavioural disorder[1].

Caregivers play an important role in family members who are sick, infirm or disabled. Families not only provide practical help and personal care but also give emotional care and support to the family member with mental disorder. These demands can bring significant levels of stress for the caregiver and can affect their overall quality of life including work, socializing and relationships. Caring for a relative with a mental health problem is not a static process since the needs of the care recipient alter as their condition changes. Caring for someone with a mental disorder can affect the dynamics of a family. It takes up most of the caregivers time and energy and this is known as burden [2],[3],[4]. Burden is defined as presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient's significant others[5]. Burden on families and society caused by the psychiatric disorders has been the focus of research since 1960's.There has been an increasing trend all over the world towards treating psychiatric patient in their family settings and in their own community, rather than in mental hospitals. While the policy of treating mental patients at home reduces the load on hospitals, help early recovery and prevent chronic handicap, it perhaps increases the burden on the family and community[6]. The families of mentally ill patients are required not only to provide physical and emotional support, but also to bear the negative impact of stigma and discrimination present in all parts of the world[1].

Bipolar affective disorder (BPAD) and Alcohol dependence syndrome (ADS) are common mental disorders and the focus of research is more on patients than on caregivers. Over the past several decades, evidence has been accumulating that mood disorder imposes substantial societal burdens[7].

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Many respondents consider violent behavior in acute mania and suicide threats or attempts in depressive episodes as the most troubling characteristics of illness. Spouses reported financial difficulties and unemployment as the most troubling prolonged consequences of affective illness[8]. Financial burden, disruption of family routine, family leisure and family interaction are also experienced as burdensome. The emotional health of caretakers was affected in a number of cases, with many reporting loss of sleep or appetite and constant worrying[9]. The most frequently experienced psychological problems were relationship problems, including interpersonal conflicts with family & friends, marital difficulties, job & school related problems, physical health problems and alcohol and substance abuse[10].

The presence of individual with alcohol or drug dependence in the family affects various aspects of family like leisure time activities, family and social relationships and finances. Family member's energies become centered on the individual with drug or alcohol dependence which leads to the development of co-dependence. Their own personal needs, creativity and sexual and aggressive urges were suppressed. These processes block the growth and development in the cognitive, emotional and spiritual aspects of the individual, and over a period of time, the co-dependent spouse may become prone to stress related diagnosable psychiatric disorders. Impairment in husband's financial and legal problems (e.g.: arrest, court cases, imprisonment etc) are the major stresses for the wives of individuals with drug or alcohol dependence[11].

Most of the western studies are about the Global Burden of the disorder. There are few studies on burden in BPAD and major focus was on Depressive disorder. There are studies dealing with problems faced by the family due to alcohol use of the patient. But less attention is given to the assessment of burden on caregivers of ADS. In this background, the present study was planned to assess and compare the burden in BPAD and ADS.

2.Methodology

This is a cross sectional hospital based comparison study. Sample consisted of two groups of patients, one diagnosed as BPAD and the other as ADS. The patients were recruited into the study from the Psychiatry OPD of hospitals providing clinical services to J.J.M.Medical College. Patients aged between 18 -60 years, belonging to both the sexes, having illness of at least 2 years were recruited in to the study. Those cases who were having concomitant mental retardation, physical illness., personality disorder, other psychiatric illness, and Alcohol dependence in cases of BPAD and BPAD in Alcohol dependence syndrome were excluded from the study . The primary family care-giver was one who met at least three of the following criteria: Is a spouse / parent or spouse equivalent, Has the most frequent contact with the patient, Helps to support the patient financially, Has most frequently been collateral in the patient's treatment, Is contacted by treatment staff in case of emergency [12].

Consent was taken from the patients and caregivers for the study. Diagnosis of BPAD and ADS was made according to DSM-IVTR. After eliciting the sociodemographic data, Burden was assessed using Burden Assessment schedule (BAS)[13]. This schedule contains 40 questions rated on a three-point scale marked from 1 to 3. The responses are 'not at all', 'to some extent' or 'very much'. The scale has nine factorial configurations, spouse-related, physical and mental health, external support, caregiver's routines, support of the patient, taking responsibility, other relations, patient's behaviour and caregiver's strategy. The minimum total score of burden in BAS is 40 and the maximum score in 120. In this study the severity of burden was categorized into 4 groups, in the following way, 40-60 – Minimum burden, 61-80 – Moderate burden,81-100 – Severe burden, and 101- 120 – Very severe burden. The burden was assessed both during the episode and one month prior to the episode in caregivers. Severity of alcohol dependence was measured using Short Alcohol Dependence Data (SADD) Questionnaire[14]. It has 15 items, each item has four choices of response, and they are: never, sometimes, often and nearly always. Each response carries a score of 0, 1, 2 and 3 respectively .Total score of all these items is calculated and severity is graded as follows 0- No dependence,1-9 – Low dependence,10-28 - Moderate dependence,30 and above – Severe dependence

Results obtained were analyzed using descriptive and inferential statistical methods. Chi square test was used for categorical data and Students t test and ANOVA for continuous data.

3.Results:

The study sample consisted of caregivers of 30 BPAD patients and 33 ADS patients. Socio demographic characteristics of the patients were comparable in both groups except for gender where males outnumbered in ADS group. The duration of the illness was more in ADS group than in BPAD group (Table-1). The caregivers of BPAD patients were older compared to the caregivers of ADS patients and there were more females and spouses as the caregivers in the ADS group than in BPAD group.

The total burden in BPAD group appeared to be more than in ADS group, but this difference was not statistically significant. The routine of caregivers of BPAD patients were significantly more affected than that of ADS patients. The difference in all other domains between the groups was not statistically significant (Table- 2). The caregivers of BPAD patients perceived significantly more burden during the episode of BPAD than one month prior to the episode (Table -3). Scores on all the domains in the caregivers of severe alcohol dependence group appeared more than in low and moderate alcohol dependence group and the difference in between the three groups was statistically significant in caregivers routine, support of the patient, taking responsibility and on total burden(Table-4)

During the episode two thirds of caregivers experienced significant burden, whereas one month before the episode only 3.33% - experienced very severe burden. During manic episode three fourth of care givers experienced significant burden while almost all caregivers reported significant burden during mixed episode. On the otherhand depressive episodes was severely burdensome to only 17% of care givers. Nearly one half of caregivers of ADS patients experienced significant burden.

Table-1: Sociodemographic Factors and duration of illness in BPAD And ADS Groups

Variables		BPAD n = 30	ADS n = 33	Statistical analysis p<0.05
Age (yrs) (Mean and standard deviation)		33.97 ± 9.8	37.76 ± 7.84	t = 1.69df = 61 N.S
Sex	Male	14	30	x^2 = 14.86
	Female	16	3	Sig
Marital status	Unmarried	10 (33.3%)	4 (12.12%)	
	Married	14 (46.6%)	28 (84.84%)	
	Separated / Divorced	6 (20%)	1 (3.03%)	
Socioeconomic status	High	7	7	x^2 = 0.551
	Middle	5	8	df = 2
	Low	18	18	NS
Duration of illness (yrs)		8.03 □ 5.09	12.85 □ 7.17	t = 2.99 Sig

(Figures in parenthesis are percentages)

Table 2: Burden In Different Domains In BPAD And ADS Groups

Variables	BPAD n = 30	ADS n = 33	Statistical analysis df = 61 p<0.05	CI 95%
Spouse related	9.77 ± 2.28	9.24 ± 2.28	t = 0.9NS	-1.67 – 0.63
Physical and mental health	14.4 ± 2.79	12.88 ± 3.88	t = 1.7NS	-3.23 – 0.19
External support	8.63 ± 3.12	8.79 ± 2.96	t = 0.20NS	-1.38 – 1.67
Caregivers routine	12.43 ± 2.82	9.52 ±2.76	t = 4.14Sig	-4.32 – - 1.5
Support of patient	8.13 ± 2.29	8 ± 2.32	t = 0.23NS	-1.29 – 0.25
Taking responsibility	8.40 ± 2.13	7.64 ± 1.92	t = 1.5NS	-1.78 – 0.25
Other relation	5.23 ± 2.13	5.58 ± 1.92	t = 0.26NS	-0.68 – 1.36
Patients behavior	8.63 ± 1.99	8.09 ± 1.94	t = 0.98NS	-1.53 – 0.45
Caregivers strategy	8.43 ± 2.24	8.03 ± 2.31	t = 0.69NS	-1.55 – 0.75
Total	83.83± 17.35	77.27 ± 16.46	t = 1.5NS	-15.08 – 1.95

Table 3 : Burden In Patients Having BPAD During Episode And 1 Month Prior To The Episode

Variables	BPAD with episode n = 30	1 month prior to episode n = 30	Statistical analysis df =29 p<0.05	CI 95%
Spouse related	9.77 ± 2.28	7.5 ± 2.16	t = 4.6Sig	1.26 – 3.27
Physical and mental health	14.4 ± 2.79	7.3 ± 2.48	t = 11.73Sig	5.86 – 8.34
External support	8.63 ± 3.12	7.37 ± 3.06	t = 4.35Sig	0.67 – 1.86
Caregivers routine	12.43 ±2.82	5.63 ± 1	t = 14.0Sig	5.8 – 2.59
Support of patient	8.13 ± 2.29	6.23 ± 1.83	t = 5.58Sig	1.20 – 2.59
Taking responsibility	8.40 ± 2.13	6.23 ± 2.01	t = 6.59Sig	1.49 – 2.84
Other relation	5.23 ± 2.13	3.9 ± 1.6	t = 4.68Sig	0.75 – 1.95
Patients behavior	8.63 ± 1.99	4.97± 1.4	t = 40.78Sig	2.97 – 4.36
Caregivers strategy	8.43 ±2.24	5.07 ± 1.7	t = 11Sig	2.74 – 3.99
Total	83.83± 17.35	54.53 ± 13.50	t = 12.34 Sig	34.15 – 24.44

Table 4 : Burden Based On Severity Of Alcohol Dependence

Variables	Low n = 3	Moderate n = 12	Severe n = 18	Statistical analysis df=2,30 Sig
Spouse related	6.66 ± 3.05	9.08 ± 2.60	9.77 ± 1.66	F=2.7*NS
Physical and mental health	11.33 ± 2.52	11.75 ± 4.57	13.89 ± 3.41	F = 1.39NS
External support	10.66 ± 0.58	7.75 ± 2.70	9.16 ± 3.18	F = 1.55NS
Caregivers routine	6.33 ± 0.58	8.58 ± 2.74	10.66 ± 2.37	F = 5.4 Sig *,**
Support of patient	5.33 ± 2.30	7.16 ± 2.16	9 ± 1.91	F = 5.75 Sig *,**
Taking responsibility	5.66 ± 2.08	6.83 ± 1.33	8.5 ± 1.82	F = 5.8 Sig *,**,***
Other relation	4.66 ± 2.08	5.25 ± 1.95	5.94 ± 1.89	F = 0.83 NS
Patients behaviour	8.66 ± 0.58	7.41 ± 2.77	8.44 ± 1.78	F = 1.17NS
Caregivers strategy	7 ± 1.73	7.41 ± 2.54	8.61 ± 2.17	F = 1.31NS
Total	66.33 ± 1.8	70.25 ± 17.4	83.77 ± 13.81	F = 3.7Sig

*The difference between Low dependence group and Moderate dependence group was significant.
** The difference between Moderate dependence group and Severe dependence group was significant.
*** The difference between Low dependence group and Severe dependence group was significant.

4.Discussion:

Family of the mentally ill person is important in treatment as they are the persons responsible for taking care of the patient once the patient is discharged and gets into the community. There are studies to report that the burden on the caregivers of psychotic illness is significant .But there is paucity of literature about the burden on caregivers of patients having ADS and non psychotic illness. The present study arose from the concern that ADS patients have considerable psychosocial problems which influence the lives of family member and can cause significant burden. So far there has not been any research in comparing the burden of caregivers of BPAD and ADS patients.

In the current study during the episode in BPAD, 33% had mild to moderate burden and 67% had significant burden. Whereas, 1 month prior to episode, 96% of caregivers considered this illness as mild - moderate burden, 4% - had significant burden. Perlick et al [15] reported that 93% of caregivers had moderate degree of burden in at least one domain,54% had severe distress in one or more, 33% in two or more and 13% in all burden domains . Domain wise assessment of burden was not done in our study. In the current study, the caregivers perceived burden both during the episode and also 1 month prior to episode. The burden experienced during the episode was significantly more than the burden before episode. This is in accordance with the Targum et al[8] who observed that bipolar illness creates burden both during acute phases and between the episodes. In the present study 33 % of BPAD patient were unmarried. About 14% of married patients were separated or divorced from their spouses. This is much lower than Brodie et al[16] who reported that 57% of BPAD patients who had been married had been subsequently divorced or separated. Burden experienced by spouses can affect the marital life .Separation or divorce can be an indirect expression of burden. Low rates of separation or divorce in BPAD patients in our study may reflect lower burden experienced different types of coping or the extent of social support.

In this study 76% of caregivers considered the manic episode as severe to very severe burdensome and this is in accordance with Targum et al [8] who reported that 77% of spouses of patients having mania considered this illness to be high to extreme burden to them. In this study 50% of caregivers considered depressive episode to be moderate burden to them and about 17% considered it to be severe burden. However, Targum et al [8] observed that 72% spouses of patients having depression considered this to be high to extreme burden to them. Manic symptoms are overtly observed and can disrupt the family environment .It is also possible that manic symptoms in the subcontinent tend to be more severe than in the west. In our culture depression is recognized and reported less by the patients and caregivers have difficulty in appreciating depressive features experienced by the patient.

In the present study the domains pertaining to care givers physical & mental health, caregivers' routine, spouse related, patients behavior and external support were more affected in the caregivers of BPAD during the episode. Similar findings have been reported by Chakrabarthi et al[9] that financial burden, disruption of family routine, family crises and family interaction were burdensome. Maximum burden was experienced in the area of disruption of family routine followed by disruption of family interaction. Perlick et al [15] has reported that about 91% caregivers considered problem behaviors as moderate to severe burden, 82% caregivers considered adverse effects on others as burdensome, and 65% caregivers considered role dysfunction of patients as burdensome

The caregivers of alcohol dependent patients experienced it as a burden. About 55% of the caregivers experienced it as mild burden - moderate burden, 45% considered it to be - significant burden. The burden was experienced more in the following domains-physical and mental health, spouse related, caregivers routine, external support, patients behaviour, caregivers strategy. However Bhowmick et al [10] reported that the presence of individual with alcohol or drug dependence in the family affects various aspects of family like leisure time activities, family and social relationships and finances. The perceived and experienced stress and its consequences depend on the degree of tolerance and acceptance of the behaviour of individual with alcohol or drug dependence by the family members.

In this study the total burden in BPAD group appeared to be more than in ADS group, but this difference was not statistically significant. Caregivers routine was affected more in the caregivers of BPAD patients than in caregivers of Alcohol dependence and this difference was statistically significant. Patients having BPAD tend to stay off work and spend more time at home than patients having ADS, who can still work during day time despite their problems. There are no comparable studies available to evaluate these findings.

There were some limitations in the study. It was a hospital based cross sectional study on a small group of patients. Other factors which influence experience and reporting of burden like social support and expressed emotions were not taken into account. Hence generalization of the findings will be difficult. Further studies are required to replicate the findings of this study.

To conclude both the disorders put significant burden on the caregivers. There was no difference in the extent of burden experienced by the caregivers in BPAD and ADS, but the pattern of burden differed. Burden is not limited to only severe mental disorders like psychosis, but can also be seen in other mental disorders like Alcohol Dependence Syndrome in a different pattern.

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