



## A EXPLORATORY STUDY TO ASSESS THE BURDEN ON CAREGIVERS AND DISABILITY IN PATIENTS HAVING BIPOLAR AFFECTIVE DISORDER AND ALCOHOL DEPENDENCE IN SELECTED AREAS OF MUMBAI

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### ABSTRACT

**Background:** Bipolar affective disorder (BPAD) and Alcohol dependence Syndrome (ADS) are two psychiatric disorders which are commonly seen now a days in maximum population in different age groups. This study evaluate the burden of patients care giver suffering from BPAD and ADS Also problem faced by them in day to day life while caring disable patients. Burden on caregivers and disability in patients having Alcohol dependence has not received attention in research so far.

**Aim:** To Explore The Burden on Caregivers and Disability In Patients Having Bipolar Affective Disorder and Alcohol Dependence In Selected Areas of Mumbai.

**Materials and Methods:** A Exploratory study among 63 patient in total (Bipolar Affective Disorder-(30), Alcohol Dependence Syndrome-(33)) were taken up for study, where by Burden of care givers and Disability score was derived from Prasad's socioeconomic status scale, Burden Assessment Schedule (BAS), Indian Disability Evaluation and Assessment Scale (IDEAS). Severity of Alcohol dependence was measured by Short Alcohol Dependence Data (SADD) Questionnaire. The burden and disability were assessed in the two groups and compared.

**Statistical Analysis:** Data was stored in MS-Excel, statistical analysis was done in In-Stat Software, For comparison of burden and disability data we had applied descriptive and inferential statistical method Chi Square Test used for categorical data and student t test and ANOVA for continuous data,  $p < 0.05$  was considered as statically significance.

**Results:** BPAD Patients burden experience more during the Episode and The comparisons Score of burden of care givers of BPAD and ADS has no difference. Whereas disability was significantly more in ADS Patients.

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**Conclusions:** Burden and disability are not limited to only severe mental disorders like psychosis, but is also seen in mental disorders like Alcohol Dependence Syndrome.

**Keywords:** Burden; disability; bipolar affective disorder; alcohol dependence syndrome.

## 1. INTRODUCTION

World Health Organization, Burden of Mental and Behavioural Disorders, The World Health Report, Mental health: New understanding, New hope ; Geneva, World Health Organization 2001 [1] Mental and Behavioural disorder are common, affecting more than 25 % of all people at some time 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.

Judd LL, et al studied [2] Bipolar Affective disorder is an episodic illness in which episodes of depression / Mania/ Mixed / Hypomania occur. BPADs are dimensional illnesses in which patient's experience, during long term course of illness, fluctuating levels of severity of manic and depressive symptom interspersed with symptom free (euthymic) periods.

As per the National Sample Survey Organization (NSSO) 2007 statistics, 1.9% of India's population is disabled in one way or the other [3]. Psychiatric disorders account nearly about 31% of world's disability. Five of the 10 leading causes of disability are in the category of mental disorders: Major depression, Alcohol use, bipolar affective disorder, Schizophrenia and Obsessive-compulsive disorder. These disorders impact negatively on the academic, occupational, social and familial functioning of the patients. Global burden of disease identified BPAD as the sixth leading cause of disability during middle years of life [1].

### 1.1 Need of this Study

Mental and Behavioural disorder are common, affecting more than 25 % of all people at some time 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.

Bipolar Affective disorder is an episodic illness in which episodes of depression / Mania/ Mixed / Hypomania occur. BPADs are dimensional illnesses in which patient's experience, during long term course of illness, fluctuating levels of severity of manic and depressive symptom interspersed with symptom free (euthymic) periods.

Alcohol dependence is a maladaptive pattern of substance use for period 12 months, which is characterized by tolerance, withdrawal symptoms, loss of control and craving.

The current prevalence of Bipolar Affective Disorder (BPAD) is 0.4-0.5%, 1-year prevalence is 0.5-1.4% and life time prevalence is 2.6 – 7.8 %. In India the prevalence of affective disorder ranges from 0.51 per thousand population to 20.78 per thousand population. The 1-year prevalence of alcohol abuse and dependence is estimated to be 6% or more. General population surveys in India have reported a Prevalence of Alcohol use ranging from 1.15-to 50 % [1].

Burden is defined as presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient's significant others. Families of patients with mental illness face stigmatization, long-term economical and emotional burden of taking care of the patient. Illness in the patient has impact on the work, social relationship and leisure activities of family members. This evokes different feelings in the family members, which can have impact on the course and prognosis of the illness.

Alcohol ranks high as a cause of disease burden. The Global Burden of Disease project, estimates alcohol to be responsible for 1.5% of all deaths and 3.5% of the total DALY's (Disability Adjusted Life Year). This burden includes physical disorder & injuries. Alcohol imposes a high economic cost on society. One estimate puts the yearly economic cost of alcohol abuse in U.S to be \$ 148 billion. Studies in other countries have estimated the cost of alcohol related problems to be around 1 % of the gross domestic product.

According to International Classification of Impairment, Disability and Handicap (ICIDH, 1980), disability is defined as interference with activities of the whole person in relation to the immediate environment. Within the ambit of definition of disability under the Persons with Disabilities Act 1995, mental illness means a disorder of the mind that results in partial or complete disturbance in the person's thinking, feeling and behaviour which may also result in recurrent or persistent inability or reduced ability to carry out activities of daily living, self-care, education, employment, and participation in social life [2].

## 1.2 Objectives of the Study

1. To assess the Burden on caregivers and Disability in patients diagnosed as Bipolar Affective Disorder and Alcohol Dependence Syndrome.
2. To compare Burden on caregivers and Disability in patients having Bipolar Affective Disorder and Alcohol Dependence Syndrome.

## 1.3 Hypothesis

1. **H1** - There will be no difference in burden on caregivers and disability in patients with Bipolar Affective Disorder and Alcohol Dependence Syndrome.
2. **H2** - There will be difference in burden on caregivers and disability in patients with Bipolar Affective Disorder and Alcohol Dependence Syndrome.

## 2. REVIEW OF LITERATURE

The review of literature for the present study is organized as follows;

### 2.1 Studies Related to Burden in Mental Disorders

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, and may help early recovery and prevent chronic handicap, it perhaps increases the burden on the family and community [4].

Mills [5] studied a group of unselected psychiatric patients. Practically all were source of anxiety to their relatives. More than 50% were described as difficult at home and only 12% caused no practical difficulties. Burdensome symptoms were that patients might be a danger to themselves or others and problems frequently arose with neighbours as a result of the patient's behaviour. Many relatives complained of disturbed nights, and reported that practical problems caused fewer difficulties than the patient's strange fancies or dumb apathy. Those patients who did not speak often created more distress than those whose speech was excessive, though the latter caused suffering too [5].

### 2.2 Studies Related to Disability in Mental Disorders

Wilder CS [6]. Stewart AL [7], Ware JE, Brook RH [8], Physical functioning refers to the ability of an individual to carry out daily activities such as dressing and bathing, the capacity to perform physical tasks such as exercise, and the extent of any restriction in physical activity such as partial or complete days of rest in bed (bed days) [6,7].

Allen et al [8]. Reported that disabilities restrict performance of social roles; limit the ability of the patient to function at expected levels; and often the signal that disease exists that requires diagnosis and treatment [8].

### 2.3 Studies Related to Burden in Bipolar Affective Disorder

Cohen MD, et al [9]. Descriptive case studies have portrayed the patient having manic-depressive illness as an individual who forms markedly dependent relationships with demands for attention & love that are never reciprocal, has a low frustration tolerance, relies on manipulation, coercion, pity and submission to attain unsuitable needs [9].

Janowsky et al [10]. Reported that the well spouse often believed that the manic phase was wilful, spiteful act, whereas the patient felt unfair, victimized and blamed for things beyond his control. In similar manner, the withdrawal, helplessness, and suicidal tendency manifested during acute depressive episode may be constructed differently by family members [10].

### 2.4 Studies Related to Disability in BPAD

Tsuang MT [11]. Long term outcome studies have found that nearly one third of manic patients have poor work performance & adjustment in other areas at 30 years follow-up [11].

Assistant Secretary for the US Department of Health, Education Welfare Baltimore [12] it has been reported that, on an average, a woman with onset of the illness at 25 years of age may lose 9 years of life, 12 years of normal health and 14 years of effective functioning without sufficient treatment [12].

## 3. METHODOLOGY

Subjects for the study were selected in two groups.

- a) Group I consisted of 30 patients diagnosed to have Bipolar Affective Disorder (BPAD Group).

- b) Group II consisted of 33 patients diagnosed to have Alcohol Dependence Syndrome (ADS Group).

The patients were recruited into the study from the Psychiatry OPD of hospitals providing clinical service to Sir J.J. Hospital and Grand Medical College, Mumbai. Patients were selected consecutively. SIR J J hospital Byculla Mumbai, with total bed strength of 1500, catering to the needs for patients mainly from central and new Mumbai. It has emergency, in-patient facilities for more than 50 patients, as well as out-patient and community services in psychiatry department.

### 3.1 Method of Collection of Data

#### 3.1.1 Sampling technique

- a) Group I consisted of 30 patients diagnosed to have Bipolar Affective Disorder (BPAD Group).
- b) Group II consisted of 33 patients diagnosed to have Alcohol Dependence Syndrome (ADS Group) by Non -Probability purposive sampling.

#### 3.1.2 Sampling procedure

Initial contact was made in Psychiatry OPD and the patients having BPAD and ADS were identified.

Patients satisfying the inclusion and exclusion criteria were Consecutive patients attending the Psychiatry OPDs of hospitals attached to Sir J.J. Medical College, diagnosed as BPAD and Alcohol dependence according to DSM -V criteria who met the inclusion criteria and did not get excluded were included in the study.

The socio-demographic data was collected on a semi – structured pro-forma.

#### 3.1.3 Inclusion criteria for cases

- Age : 18-60 years
- Both Male and Female.
- Duration of illness at least 2 years
- Patients who are willing to participate.

#### 3.1.4 Exclusion criteria for cases

- Concomitant mental retardation
- Concomitant physical illness
- Concomitant personality disorder.

#### 3.1.5 Type of the study

It was a Cross Sectional Hospital based Comparison study conducted during the study period of August 2016 to December 2018.

#### 3.1.6 Instruments of assessment

- 1) Informed consent form.
- 2) Pro-forma to elicit socio-demographic data.
- 3) Prasad's socioeconomic status scale.
- 4) DSM-V criteria for Bipolar Affective disorders and Alcohol Dependence Syndrome.
- 5) Burden Assessment schedule (BAS).
- 6) Indian Disability Evaluation and Assessment Scale (IDEAS).
- 7) Short Alcohol Dependence Data (SADD) Questionnaire.

### 4. RESULTS

The Table 1 shows that socio demographic variables like Age, Sex, Place, Religion, Education, Occupation, Type of family, marital status, and Socio economic status shows difference between the two groups was not statistically significant.

#### 4.1 Age

The mean of age of caregivers of BPAD patients were found to be greater than the caregivers of alcohol dependent patients and this difference was statistically significant.

#### 4.2 Sex

Caregivers of BPAD patients were females and this difference between the two groups was statistically significant.

#### 4.3 Occupation

In ADS groups 54% of caregivers were housewives where as in BPAD group 66% were in unskilled work.

#### 4.4 Relation

In ADS group greater number of caregivers were spouses the difference between the two groups was significant.

The duration of illness in alcohol dependent patients appeared greater than in BPAD group, and the difference between the two groups was statistically significant.

The total burden in BPAD group appeared to be more than in ADS group, but this difference was not statistically significant.

The disability in BPAD patients appeared to be more than in ADS patients and this difference was found to be statistically significant.

There was positive correlation between disability of patients and burden on care givers of patients having BPAD.

There was positive correlation between disability of patients and burden on caregivers, Severity of Alcohol dependence and Burden on caregivers, Severity of Alcohol dependence and disability of patients.

## 5. DISCUSSION

### 5.1 Sociodemographic Variables

**In patients:** ADS group had more male patients than BPAD group and this difference was statistically significant.

**Burden in caregivers of BPAD patients:** In the present study 10% of the caregivers considered BPAD as mild burden, 23% - moderate burden, 53%- severe burden and about 13% - as very severe burden to

them. Whereas, 1 month prior to episode, 73% of caregivers considered this illness as mild burden, 23% - moderate burden, 3% - very severe burden to them.

**Disability in BPAD patients:** In this study during the episode about 17% had mild disability, 50% - moderate disability, 33%- severe disability.

**Burden and disability in alcohol dependence:** The caregivers of alcohol dependent patients experienced it as a burden. About 18% of the caregivers experienced it as mild burden, 36% - moderate burden, 39% - severe burden, 6% - very severe burden

**Comparison of burden in BPAD and ADS:** 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.

**Table 1. Socio-demographic factors of BPAD and ADS**

Variables		BPAD (n = 30)	ADS (n = 33)	Statistical Analysis	p-value
<b>Age (yrs.)</b> (Mean $\pm$ standard deviation)		33.97 $\pm$ 9.8	37.76 $\pm$ 7.84	t = 1.70	0.094
Sex	Male	14(46.67%)	30(90.9%)	$\chi^2 = 12.58$ df=1	0.0004*
	Female	16(53.33%)	3(9.1%)		
Place	Rural	15(50%)	19(57.58%)	$\chi^2 = 0.12$ df=1	0.73
	Urban	15(50%)	14(42.42%)		
Religion	Hindu	27(90%)	30(90.9%)	$\chi^2 = 0.015$ df = 1	0.90
	Muslim	3(10%)	3(9.1%)		
Education	No education	13(43.33%)	9(27.27%)	$\chi^2 = 1.795$ df=2	0.41
	Up to 10	13(43.33%)	18(54.55%)		
	Above 10	4(13.33)	6(18.18%)		
Occupation	Housewives	5 (16.6%)	3 (9.09%)	$\chi^2 = 4.17$ df=3	0.24
	Skilled job	3 (10%)	8 (24.2%)		
	Unskilled job	17 (56.6%)	20 (60.6%)		
	Unemployed	5 (16.6%)	2 (6.06%)		
Type of family	Nuclear	21(70%)	23(69.7%)	$\chi^2 = 0.0007$ df=2	0.98
	Joint	9(30%)	10(30.3%)		
Marital status	Unmarried	10 (33.3%)	4 (12.12%)	$\chi^2 = 10.69$ df=2	0.0048*
	Married	14 (46.6%)	28 (84.84%)		
	Separated	6 (20%)	1 (3.03%)		
Socioeconomic Status	High	7(23.33%)	7(21.21%)	$\chi^2 = 0.39$ df=2	0.82
	Middle	5(16.67%)	8(24.24%)		
	Low	18(60%)	18(54.55%)		

\*Significant when  $p < 0.05$ , (Figures in parenthesis are percentages) BPAD-Bipolar Affective Disorder, ADS-Alcohol Dependence Syndrome

**Table 2. Socio-demographic factors of caregivers of BPAD AND ADS group**

Variables		BPAD n = 30	ADS n = 33	Statistical Analysis	p-value
Age (yrs.) (Mean $\pm$ standard deviation)		45.2 $\pm$ 11.64	33.03 $\pm$ 9.17	t=4.63	<0.0001*
Sex	Male	17(56.67%)	3(9.1%)	$\chi^2 = 8.002$ df=1 (Sig)	0.0047*
	Female	13(43.33%)	30(90.9%)		
Education	No education	17(56.67%)	21(63.64%)	$\chi^2 = 2.283$ df=2	0.32
	Up to 10 <sup>th</sup> std.	10(33.33%)	6(18.18%)		
	Above 10 <sup>th</sup> std.	3(10%)	6(18.18%)		
Marital status	Married	30 (100%)	30 (90.9)	$\chi^2 = 2.86$ df=1	0.09
	Unmarried	0	3 (9.09%)		
Occupation	Unemployed	0	3 (9.09%)	$\chi^2 = 17.14$ df=3	0.0007*
	Housewives	4 (13.2%)	18 (54.5%)		
	Skilled	6 (20.1%)	2 (6.06%)		
Relation	Unskilled	20 (66.6%)	10 (30.30%)	$\chi^2 = 8.27$ df=1	0.0040*
	Spouse	11(36.67%)	25(75.76%)		
	Others	19(63.33%)	8(24.24%)		

\*Significant when  $p < 0.05$ , (Figures in parenthesis are percentages) BPAD-bipolar affective disorder, ADS-alcohol dependence syndrome

**Table 3. Comparison of duration of illness in BPAD and ADS groups**

Variable	BPAD n = 30	ADS n = 33	Unpaired t-value	95% CI
Duration of illness (years)	8.03 $\pm$ 5.09	12.85 $\pm$ 7.17	2.99	1.59 – 8.03

S-Significant when  $p < 0.05$

**Table 4. Comparison of total burden in BPAD and ADS groups**

Variable	BPADn = 30	ADSn = 33	Unpaired t-value	95% CI
Total burden Score	83.83 $\pm$ 17.35	77.27 $\pm$ 16.46	1.5	15.08 – 1.95

NS-Not Significant, when  $p > 0.05$

**Table 5. Comparison of total disability in BPAD and ADS groups**

Item	BPAD N=30	ADSN=33	Unpaired t-value	95% CI
Total score	12.64 $\pm$ 3.24	8.15 $\pm$ 3.21	4.12	1.6 – 4.7

S-Significant when  $p < 0.05$

**Table 6. Correlation between disability and burden in BPAD**

Correlation	r	Statistical significance
IDEAS and BAS	0.51	$p < 0.05$

S-Significant when  $p < 0.05$

**Table 7. Correlation between disability, burden and severity of dependence in ADS**

Correlation	r	Statistical significance
IDEAS and BAS	0.59	$p < 0.05$
SADD and BAS	0.49	$p < 0.05$
SADD and IDEAS	0.55	$p < 0.05$

S-Significant when  $p < 0.05$

**Disability in BPAD and ADS:** The disability in BPAD patients appeared to be more than in ADS patients and this difference was found to be statistically significant. This could be due to more disabling clinical symptoms in BPAD than in ADS patients.

## 6. CONCLUSION

There was no significant difference in socio-demographic details of patients between the BPAD and ADS group except for the sex of the patients. Male patients were more in ADS group than in BPAD group. The mean age of caregivers of BPAD group was found to be greater than the caregivers of ADS group and this was statistically significant. There were significantly more female caregivers and spouses as caregivers in ADS group than in BPAD group. The duration of illness was significantly more in ADS group than in BPAD group.

During the episode 10% of caregivers considered BPAD as mild burden, 23.3%-moderate burden, 53.3%-severe burden, and 13.3%- very severe burden.

In ADS group 18.18% of caregivers considered it as mild burden, 36.36%-moderate burden, 39.39%-severe burden, and 6.06%- very severe burden. There was positive correlation between disability of patients and burden on care givers of patients having BPAD. There was positive correlation between disability of patients and burden on caregivers of ADS, severity of Alcohol dependence and burden on caregivers, severity of Alcohol dependence and disability of patients.

Burden and disability are not limited to only severe mental disorders like psychosis, but can also be seen in other mental disorders like Alcohol Dependence Syndrome.

## 7. RECOMMENDATION

1. The researcher recommends to assess burden for cancer patient
2. Same study can be conducted by changing the population i.e. Patient with psychiatric disorder like depression and cognitive dysfunction.

### 7.1 Implication of Study

#### 7.1.1 Nursing education

- This study can be useful for nursing students for rendering nursing care to the BAPD patients

- It can be considered for planning alternative therapy.

#### 7.1.2 Nursing services

- There should be a provision counselling to care givers. This study will help Nursing officers to keep motivated while giving care to patients also to care giver helps to focus to achieve outstanding performance in nursing care.

#### 7.1.3 Nursing administration

- Plan of Health education to care givers of patient suffering from BAPD and ADS by administrative personnel's since they deal with nursing resource planning and managing the patient oriented activity for institutions.

## CONSENT AND ETHICAL APPROVAL

As per international standard or university standard written ethical approval has been collected and preserved by the authors.

An informed consent was obtained from Care Giver of Patient suffering from BAPD and ADS, those who were willing to participate in the study.

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I Atish Damodar Kadale declares this study conducted by me during my PhD Nursing course hence no plagiarism has to be appended. This study has been carried out with permission of SIR J J Hospital Byculla, Mumbai. I am assuring that my study is not published any were.

## COMPETING INTERESTS

Authors have declared that no competing interests exist.

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