



A Study of Caregiver Burden among Spouses of Patients with Bipolar Affective Disorder

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Abstract

Background: Bipolar affective disorder [BPAD] is characterised by recurrent episodes of hypomania, mania, euthymia and depression or a mixed state. This disabling illness causes significant degree of burden on the caregivers. A better understanding of their concerns is important to assess the course of the disease and prognosis among the patients and to improve the training of professionals working with this population. The aim of the study is to assess the family burden among spouses of patients with bipolar affective disorder in a Psychiatry Outpatient Department at Rajah Muthiah Medical College and Hospital, Chidambaram.

Methodology: This is a descriptive study. The study was conducted among patients affected with bipolar affective disorder and their spouses attending Psychiatry Outpatient Department Rajah Muthiah Medical College, Chidambaram. Socio – demographic factors of both caregivers and patients were collected using following questionnaires and Burden assessment schedule (BAS) was applied to the spouses.

Results: Higher mean scores of caregiver burden (75% above 60) was noted among spouses of BPAD patients. Male patients (76.37 ± 17.18) experience significant burden than female patients (66.38 ± 9.01) and in turn female spouses (76.79 ± 17.22) experience more burden than male spouses (66 ± 8.46). There was statistically significant different in mean BAS values among various duration of illness categories (P value <0.05).

Conclusion: Spouses in this study experienced significant burden and distress both subjectively and objectively. Female spouses experience significant caregiver burden compared to their male spouses.

Keywords: Bipolar disorder, spouses, caregiver, burden

Introduction

The prevalence of Bipolar disorder is 45 million worldwide and its incidence is 4.5 million (2017).^{1,2} Of the years of life lost due to disability (YLD) worldwide, bipolar disorders and unipolar depressive disorders account for 295 and 1500 per 100,000 population worldwide, respectively.³ Even though newer medications are used in treating Bipolar disorder, patients still continue to experience persistent residual symptoms, problems in psychosocial functioning, cognitive impairment, and poor quality of life. They are more prone to suffer

from increased mortality from co-morbid medical conditions or suicide leading to increased service utilization.

Generally, the course of illness in BPAD patients is cyclical in nature with chronic recidivating course posing unique challenges and barriers to them.⁴ Recurrent nature of the illness frequently causes morbidities and co-existing medical conditions, further leading to larger economic impact on individuals with the illness, their families, the

health system and wider society. The sudden changes in mood and behavior that characterize BD adversely affect various aspects of the lives of both patients and caregivers including employment, financial functioning, and social interactions.⁵

Caregiver burden is defined as the extent to which caregivers perceive their emotional state, physical health, social life, and financial status being affected by caring for their ill relative.⁶ Caregivers burden refers to the effect of stressors on the relatives caring for mentally ill patients.

Objective burden is related to the patient's symptoms and their effects on socio-demographic characteristics and on other factors, such as household routine, family or social relations, work, economic status and physical health.⁷ Subjective burden is related to the mental health and subjective distress like sadness, anxiety and embarrassment in social situations, the stress of coping with troubling behaviors.^{7,8}

Families in India were largely inter-dependent and there is a concern regarding one's well-being for every member of the family. Hence there used to be a high involvement of family members in treating their mentally ill relatives. Caring for a mental disorder patient can affect the family dynamics. It takes up most of the caregiver's time and energy. Caregivers experience poorer self-reported health, engage in less health promotion activities than non-caregivers, and report lower life satisfaction because of high caregiver burden and responsibilities.⁹ In Indian context, for married mentally ill persons, their spouses used to be the primary caregiver if they continue to live together. Cuijpers had found that burden in the families of patients with affective disorders is lower as compared to those with other psychiatric disorders.¹⁰ Marriage could represent a protective factor against functional impairment for bipolar disorder patients.¹¹ As per Bauer et al., major source of burden experienced by women was deterioration of the quality of relationships with their partners.¹²

Caregiver burden was positively correlated to their emotional over-involvement which was, in turn, negatively correlated with the patient's medication adherence. This implies that burden may indirectly affect the patient's treatment outcomes, which in turn may cause poorer illness behavior, and further impact the family. In other words, family burden and patient

illness can enter a vicious cycle, with each negatively impacting the other.¹³

According to Ogilvie et al, caregivers of patients with BPAD experience high levels of expressed emotion like critical, hostile and over-involved attitudes. Inter episode symptoms and subsyndromal depressive symptoms pose another potential of burden in patients with BPAD resulting in severe and wide spread functional impairment.¹⁴ Ostacher et al reported that depressive episodes were not only related with greater objective and subjective caregiver burden but also associated with significant burden even after controlling it.¹⁵

Fadden et al through Social Behavioral Assessment Schedule (SBAS) found that nearly half of spouses found work a strain as a result of the responsibilities towards the patients. Nearly half of the spouses felt that the patients had become like child, someone who needed to be looked after. Spouses felt that marital and sexual relationships were badly affected. Spouses took over various roles the patient would normally be expected to carry out and wives found this particularly difficult. Their expectations of the relationships were generally reduced and mostly women had a sense of bereavement as a result.¹⁶

Caregivers of relatives with mood disorder show a different pattern of burden and reward, overtime, depending on the patient diagnosis, however, family functioning was significantly impaired in all cases.¹⁷

Methodology

Materials & Methods

Source of data:

A cross sectional study was done during the period of August 2021- November 2021, in the Psychiatry Department of Rajah Muthiah Medical College Hospital, Chidambaram. It is a tertiary care hospital. For this study, a sample size consisting of 40 spouses of bipolar patients were included in the study.

Inclusion criteria for patients:

Diagnosed as Bipolar affective disorder according to ICD-10

Exclusion criteria for patients:

1. Comorbid physical and other Psychiatric illness
2. Organic illness

3. Associated with personality disorder or MR

Inclusion criteria for caregivers:

Spouses of the index patient who actively involved in the care of the patient and living with the patient

Exclusion criteria for caregivers:

1. Comorbid physical and other psychiatric illness
2. Associated with personality disorder or MR

Sampling methods:

Patients with a diagnosis of bipolar affective disorder and their spouses attending the Psychiatric outpatient department in Rajah Muthiah Medical College hospital, were included in the study, after getting the informed consent about the study were included.

Assessment of the study population:

Spouses were administered socio-demographic data sheet and Burden Assessment Schedule.¹⁸

Results

Fig 1: Bar chart showing age and sex wise distribution among the bipolar disorder patients.

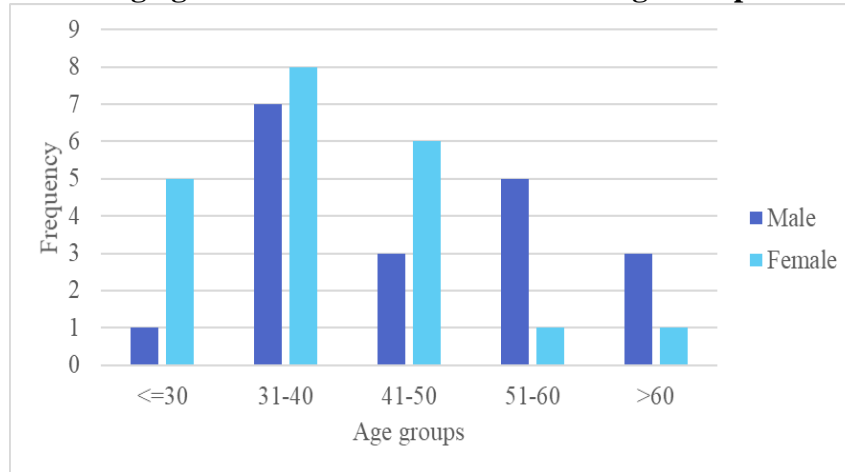
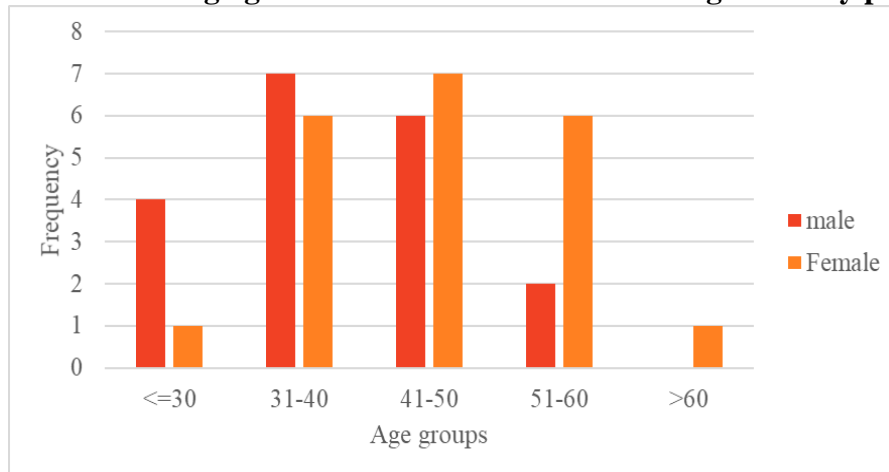


Fig 2: Bar chart showing age and sex wise distribution among the study participants

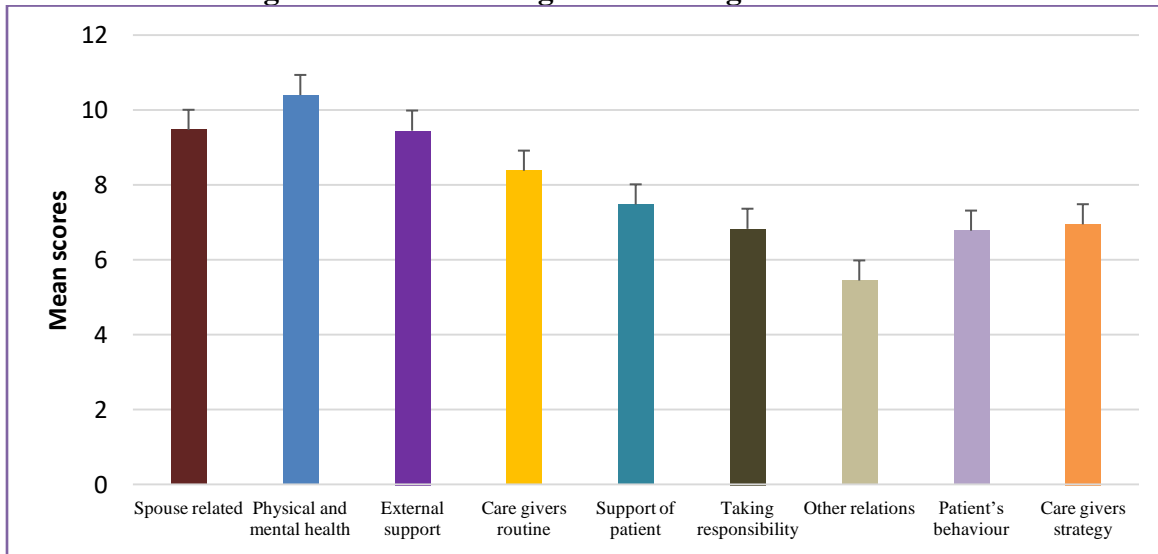


Among the participants, 32.5% were in the age group 31 to 40 years and 41 to 50 years, respectively. 47.5% of the participants were males and 52.5% of the participants were females. Among the participants, 22.5% were married for 11 to 15 years and > 25 years, respectively and 17.5% were married between 6 and 10 years. 27.5% participants had studied up to high school followed by 22.5% up to middle school. 32.5% were unemployed followed by 15% were doing unskilled job and self-employed, respectively. 27.5% belonged to lower middle class and 22.5% belonged to upper middle class. 72.5% resided in rural area and 12.5% in urban area. 87.5% were Hindus. 75% lived in nuclear family. 32.5% of the patients were having the illness for 6 to 10 years and 22.5% for up to 5 years and 11 to 15 years, respectively. 45% have been taking the treatment regularly and 55% irregularly.

Table 1: Mean scores among various categories of burden assessment schedule

Categories	Minimum	Maximum	Mean	Std. Deviation
Spouse related	6	13	9.47	1.88
Physical and mental health	6	18	10.40	3.06
External support	6	13	9.45	2.12
Care givers routine	5	15	8.38	2.37
Support of patient	5	11	7.48	1.58
Taking responsibility	4	11	6.83	1.50
Other relations	3	9	5.45	1.69
Patient's behaviour	4	11	6.78	1.83
Care givers strategy	4	12	6.95	1.58
Total score	50	103	71.13	14.26

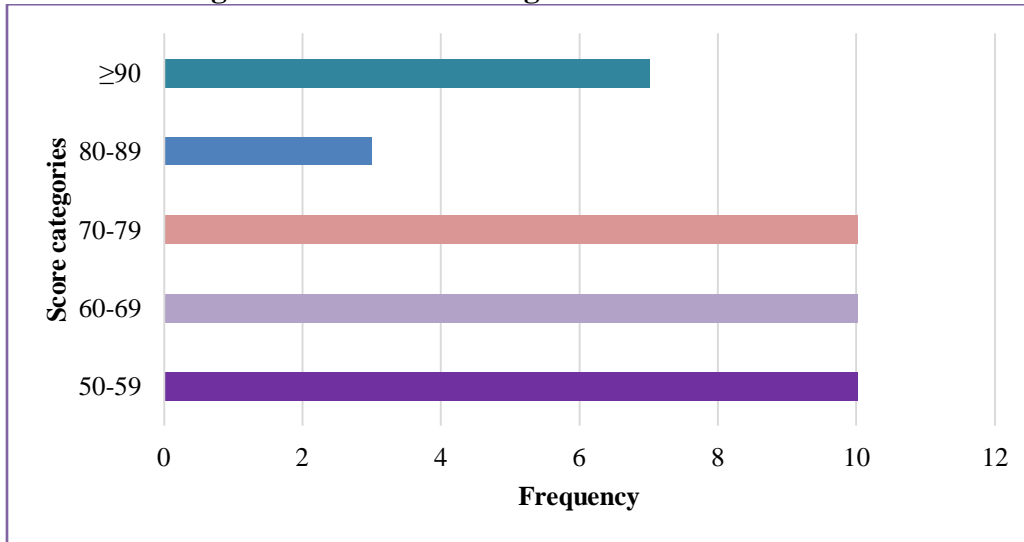
Fig 3: Bar chart showing mean scores among various categories of burden assessment schedule



1. The mean score for the questions in the spouse related category among the study participants was 9.47 ± 1.88 .
2. The mean for physical and mental health related section was 10.40 ± 3.06 .
3. The mean for external support category was 9.48 ± 2.12 .
4. The mean for care givers routine category was 8.38 ± 2.37 .
5. The mean for support of patient category was 7.48 ± 1.58 .
6. The mean for taking responsibility category was 6.83 ± 1.50 .
7. The mean for other relations was 5.45 ± 1.69 .

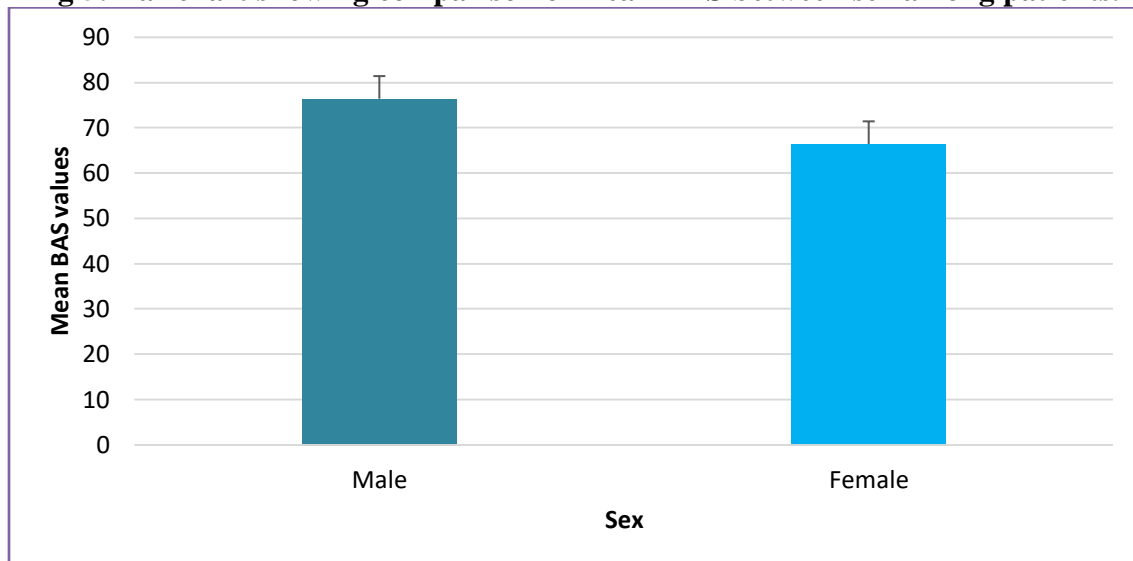
- 8. The mean for patient's behaviour was 6.78 ± 1.83 .
- 9. The mean for care givers strategy was 6.95 ± 1.58 .
- 10. The mean total score among the participants was 71.13 ± 14.26 .

Fig 4: Bar chart showing distribution according to total score of burden assessment schedule.



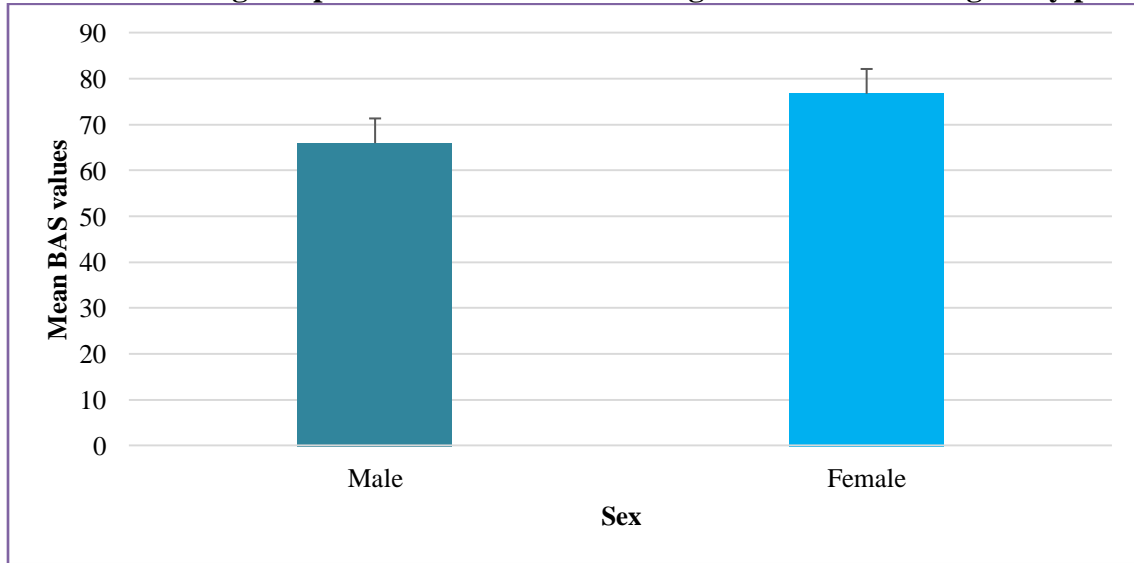
25% participants were having a score of 50-59, 60-69 and 70-79, respectively.

Fig 5: Bar chart showing comparison of mean BAS between sex among patients.



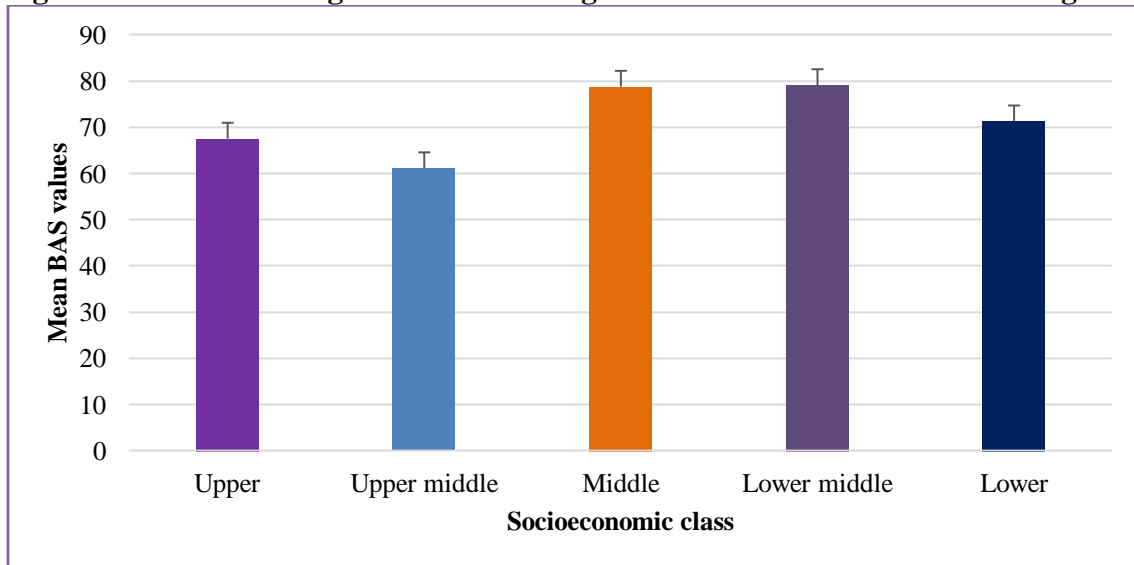
The mean BAS among the male patients was 76.37 ± 17.18 and the mean BAS among female was 66.38 ± 9.01 . The mean BAS among males was more than that of the females and the difference was statistically significant (P value < 0.05).

Fig 6: Bar chart showing comparison of mean BAS among different sex among study participants

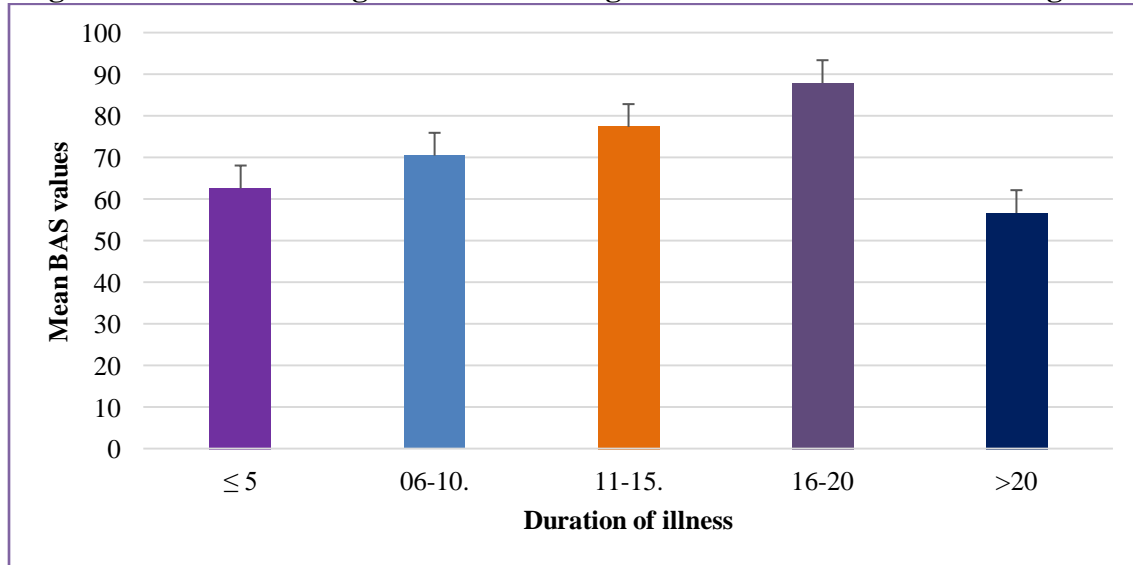


The mean BAS among the male study participants was 66 ± 8.46 and the mean BAS among female was 76.79 ± 17.22 . The mean BAS among female study participants was more than that of the male participants and the difference was statistically significant (P value < 0.05).

Fig 7: Bar chart showing mean BAS among various socioeconomic status categories



Among the participants with upper socioeconomic status, the mean BAS was 67.50 ± 11.78 , among those with upper middle class it was 61.11 ± 8.89 , among those with middle it was 78.75 ± 12.84 , among those with lower middle class it was 79.09 ± 15.08 and among those in lower class, the mean was 71.25 ± 15.22 . There was statistically significant difference in mean BAS between various socioeconomic categories. The mean was highest among the lower middle class followed by the middle class.

Fig 8 : Bar chart showing mean BAS among various duration of illness categories

Among the patients with duration of illness of less than or equal to 5, the mean BAS was 62.67 ± 7.76 , among those with duration between 6 to 10, the mean was 70.54 ± 15.07 , among those with duration between 11 and 15, the mean was 77.44 ± 11.91 , among those with the duration of 16 to 20 years the mean was 88 ± 6.96 and among those with duration more than 20 years it was 56.75 ± 6.70 . There was statistically significant different in mean BAS values among various duration of illness categories (P value < 0.05). The highest was in the 16 to 20 years category followed by 11 to 15 years category.

The study showed no significant differences in burden among various settings of the spouses like occupation, socio-economic status, marital years, residential setting as well as compliance to treatment of the patient

Discussion

This study was carried out on 40 spouses of persons diagnosed with Bipolar Affective Disorder attending the Psychiatry outpatient department at Rajah Muthiah Medical College Hospital, Chidambaram. This study was conducted in the spouses of Bipolar Affective Disorder patients to assess their caregiver burden.

Socio- demographic profile of the patient

The patients mainly belong to middle age group (37.5% in age group 31 to 40 years and 22.5% in age group 41 to 50 years) with slight female

preponderance (52.5%). Majority of patients belong to rural background (72.5%) following Hinduism (87.5%) and are living in nuclear family arrangement (75%). 55% of the patients had less than 10 years of illness and 45% of patients were regularly compliant to treatment.

Socio-demographic profile of the spouses

Majority of spouses, the study population belong to middle age group (65% in the age group 31-50 years) with slight male preponderance (52.5%). Most of the couples are in marital relationship for over 10 years (70%). 25% of the study population were graduates, 27.5% finished school education, 25% were either illiterates or had primary education. Majority of spouses were either unemployed or homemakers. The study population is distributed among various socio-economic gradients, family arrangements and location of residences.

Caregiver Burden

Spouses in this study experienced significant burden and distress both subjectively and objectively. This validates previous studies done in Indian families and over the world related to caregiver burden experienced by caregivers of patients affected with bipolar disorder.

From this study, it is found that the caregiver burden is significantly higher for male patients i.e., their female spouses are facing severe burden in taking care of the partner. The elevated burden among

females in this study setting might be due to the fact they need to cope with the problems within the home itself whereas the males have further opportunities in venting out their burden

The study revealed that longer the duration of illness, the amount of burden experienced by the spouses tend to increase validating the previous studies (Targum et al.).¹⁹ Although, the burden experienced by spouses with over 20 years of illness in patients is relatively low in this study which might be due to reduced severity of illness among their partners.

The spouses experience significant burden which mainly affect their own physical and mental health which was evident from various research literatures in both Indian context and in western settings. Even though the spouses experienced sound and serious caregiver burden, the study showed no significant differences in burden among various settings of the spouses like occupation, socio-economic status, marital years, residential setting as well as compliance to treatment of the patient.

As the illness is episodic and cyclical in nature which might tend to recur for most cases, regardless of the compliance to treatment, the study could not establish significant burden related to the compliance of treatment.

Conclusion

This cross-sectional study is done to assess the caregiver burden experienced by the spouses of bipolar affective disorder patients. Burden Assessment Schedule was administered.

Majority of the patients and spouses belong to middle age group with 55% of the patients have illness less than 10 years. The study sample comprised of population belonging to varying educational qualification, occupations and socio-economic background. Most couples are coming from rural background and living in a nuclear family arrangement.

In this study, significant amount of burden was found among spouses and burden was highest in domains-physical and mental health, spouse related and external support. From the study, the couples' demographic characteristics, socio-economic statuses have no significant influence in caregiver burden as the burden is significantly higher in all settings.

Female spouses and those with caregiver role for a long period of time are experiencing greater burden.

The main inference of our study was significant demands are being placed on the spouses of BPAD patients which in turn affect their physical and mental health, but still researches targeting this aspect were few. Future studies have to be focused on the various aspects of caregivers burden as they play an important role in the prognosis and outcome of chronic mentally ill patients like BPAD by focusing not only in the symptom recovery but also return to normal functioning and attainment of a meaningful life.

Limitations

1. The present study was done in a tertiary hospital, in a semi-urban setting and hence the results cannot be generalized to the population at large.
2. The study had been primarily cross sectional in nature and considering the chronic and episodic course of the illness, longitudinal studies could have been better.
3. The study had not considered about different phases of the illness and varying levels of burden during each phases.
4. The sample population was small in number.

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