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Research Paper

Disability of Patients and Caregiver Burden in Bipolar Affective Disorder: A Co-relational Study

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ABSTRACT

Introduction: Disability is defined as interference with activities of the whole person in relation to the immediate environment. BPAD is identified as the sixth leading cause of disability during middle years of life. Burden is defined as presence of problems, difficulties or adverse events which affect the lives of the psychiatric patient's significant others. Illness in the patient has impact on the work, social relationship and leisure activities of family members. Very few Indian studies have dealt with burden and disability and they have studied family burden. Present study is conducted to compare the caregiver burden and the disability among BPAD patients. ***Objectives:*** (i)To study the socio-demographic variables of the patient group in relation to their disability (ii) To study the patients' disability in relation to the duration of illness (iii)To study the socio-demographic variables of care givers in relation to the burden experienced by them (iv)To study the correlation between the caregiver burden and disability of the patients. ***Materials and Methods:*** This is a cross sectional hospital based study conducted over a period of six months. The study sample consisted of seventy patients diagnosed to have bipolar affective disorder and their respective care givers. Patients were administered the Indian disability evaluation and assessment scale (IDEAS) to assess their disability. Care givers were administered Family Burden Interview Schedule (FBIS) to assess the burden experienced by them. The diagnosis of bipolar affective disorder is made in accordance to ICD-10 criteria. ***Results and Conclusions:*** The mean age of the patients is 33.97 ± 9.8. Severe disability is present in younger patients, in those with low family income. The mean age of the care givers is 36.2 ±11.64. Significant amount of burden is experienced by female caregivers and in families where there is domestic violence.

Keywords: *Disability, Caregiver, Burden, Bipolar Affective Disorder*

Mental and Behavioral disorder are common, affecting more than 25 % of all people at some time during their lives. Bipolar Affective disorder is an episodic illness in which episodes of depression / Mania/ Mixed / Hypomania occur. BPADs are dimensional illnesses in which patients experience, during long term course of illness, fluctuating levels of severity of manic sand depressive symptom interspersed with symptom free (euthymic) periods.[1] The

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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 %.[2] In India the prevalence of affective disorder ranges from 0.51 per thousand population[5] to 20.78 per thousand population.[3]

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.[4] 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.[5]

BPAD has been found to be associated with the following types of disability: increased suicidal behavior, higher unemployment, higher dependence on public assistance, lower annual income, increased work absenteeism owing to illness, decreased work productivity, poorer overall functioning, lower quality of life, and decreased life span.[1] Chaudhury et al found that patients having BPAD were disabled in the following cores of functioning: self care, interpersonal relations, communication & understanding and work.[6]

Burden is defined as presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patient's significant others.[7] 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.[5] Very few Indian studies have dealt with burden and disability and they have studied family burden. There are few studies on burden and disability in BPAD and major interest was shown on Depressive disorder. With this background, the present study is conducted to compare the caregiver burden and the disability among BPAD patients.

MATERAILS AND METHODS

This is a cross sectional hospital based study. The study was conducted in the In-patient department of psychiatry, S.V.S Medical College and Hospital. This is a tertiary care hospital, providing specialist clinical care to Mahabubnagar and adjoining districts. The present study was conducted for six months i.e., from 1st of July 2018 to 31st December 2018. The study sample was collected from patients admitted for Bipolar affective disorder and their care givers. Patients were selected consecutively. The study sample consisted of seventy patients diagnosed to have Bipolar affective disorder and their respective care givers.

Patients fulfilling the selection criteria were approached and informed consent was obtained. Clinical and socio-demographic details of patients and their care givers were collected using a semi-structured proforma. Patients were administered the Indian disability evaluation and assessment scale (IDEAS)[8] to assess their disability. Care givers were administered Family Burden Interview Schedule (FBIS)[9] to assess the burden experienced by them. Assessments were cross-sectional and non-blind. The diagnosis of Bipolar affective disorder is made in accordance to ICD-10 criteria.[10]

Inclusion Criteria

1. Availability of care givers.
2. Age of patient and the care giver should be greater than 16 Years

3. Both Should be physically fit to answer the questions

Exclusion Criteria

1. Patients and their care givers taking any medication, which can produce cognitive and other psychological defect.
2. Patients and their care givers with other co-morbid general medical condition, those needing urgent attention for physical problems.
3. Patients without care givers who can give reliable and adequate information
4. Those who did not give consent for the study.

Objectives

1. To study the socio-demographic variables of the patient group in relation to their disability.
2. To study the patients' disability in relation to the duration of illness.
3. To study the socio-demographic variables of care givers in relation to the burden experienced by them.
4. To study the correlation between the caregiver burden and disability of the patients.

RESULTS

Table No-1 Comparison of Socio Demographic Variables With Disability In BPAD Patients

Variable	Mild Disability	Moderate Disability	Severe Disability	Total	Statistical Analysis
Age					X^2=9.59;Df=4 P=0.0479 (S)
16-30 Years	4(16.6%)	16(56.6%)	4(16.6%)	24(100%)	
31-45 Years	2(7.6%)	24(92.3%)	0(0%)	26(100%)	
>45 Years	0(0%)	10(100%)	0(0%)	10(100%)	
Total	6(10%)	50(83.3%)	4(6.6%)	60(100%)	
Sex					X^2=0.747;Df=2 P=0.69
Female	2(6.66%)	26(86.6%)	2(6.66%)	30(100%)	
Male	4(13.3%)	24(80%)	2(6.66%)	30(100%)	
Total	6(10%)	50(83.3%)	4(6.66%)	60(100%)	
Education					X^2=10.56;Df=6 P=0.10
Illiterate	0(0%)	4(100%)	0(0%)	4(100%)	
<5 Years	0(0%0	8(100%)	0(0%)	8(100%)	
6-10 Years	4(14.2%)	24(85.7%)	0(0%)	28(100%)	
>10 Years	2(10%)	14(70%)	4(20%)	20(100%)	
Total	6(10%)	50(83.3%)	4(6.66%)	60(100%)	
Occupation					X^2=1.125;Df=2 P=0.57
Unemployed	2(6.25%)	28(87.5%)	2(6.25%)	32(100%)	
Employed	4(14.2%)	22(78.5%)	2(7.14%)	28(100%)	
Total	6(10%)	50(83.3%)	4(6.66%)	60(100%)	
Family Income					X^2=16.69;Df=6 P=0.0105 (S)
<5000rs/M	0(0%)	18(100%)	0(0%)	18(100%)	
5000-10,000 Rs/M	2(6.66%)	24(80%)	4(13.3%)	30(100%)	
10,000-15,000 Rs/M	4(40%)	6(60%)	0(0%)	10(100%)	
>15,000 Rs/M	0(0%)	2(100%0	0(0%)	2(100%)	
Total	6(10%)	50(83.3%)	4(6.66%)	60(100%)	

Variable	Mild Disability	Moderate Disability	Severe Disability	Total	Statistical Analysis
D/O/M/L					X^2=10.205;Df=6 P=0.116
<10 Years	2(10%)	16(80%)	2(10%)	20(100%)	
11-20 Years	4(18.18%)	18(81.8%)	0(0%)	22(100%)	
21-30 Years	0(0%)	6(75%)	2(25%)	8(100%)	
31-40 Years	0(0%)	10(100%)	0(0%)	10(100%)	
Total	6(10%)	50(83.3%)	4(6.66%)	60(100%)	
Family Type					X^2=2.23;Df=2 P=0.32
Extended	2(14.2%)	10(71.4%)	2(14.2%)	14(100%)	
Nuclear	4(8.69%)	40(86.9%)	2(4.4%)	46(100%)	
Total	6(10%)	50(83.3%)	4(6.66%)	60(100%)	
Locality					X^2=4.50;Df=2 P=0.105
Urban	4(12.5%)	24(75%)	4(12.5%)	32(100%)	
Rural	2(7.14%)	26(92.8%)	0(0%)	28(100%)	
Total	6(10%)	50(83.3%)	4(6.66%)	60(100%)	

A total of sixty patients (n=60) diagnosed as having Bipolar Affective Disorder were considered for the study. Table no.1 shows the socio demographic variables in the BPAD patients. As shown in the table, the age of the patients is divided in to three categories namely 16-30 years, 31-45 years and above 46 years. The mean age of the patients is 33.97 ± 9.8. When compared with the amount of disability, it is found that severe disability is found in the age group of 16-30 years. This implies that more disability is experienced by the young people suffering from the disease than older people and the correlation is statistically significant (p=0.04).

In our study it is found that disability associated with illness is not much varied with the sex of the patient. Disability is more found in the patients whose education level is more than ten years than in patients who are less educated. When disability is compared with the employment status of the patients it is found that more disability is seen in employed population than in unemployed. Patients with family income less than ten thousand rupees per month experienced more disability. The correlation between family income and disability is statistically significant (p=0.01). Severe disability is more prevalent in urban population (p=0.10), in extended families (p=0.32) and in patients whose duration of married life is between 21-30 years (p=0.11).

Table No-2 Correlation of Duration of Illness With Disability In BPAD Patients

Variable	Mild Disability	Moderate Disability	Severe Disability	Total	Statistical Analysis
D/O/Illness					X^2=10.7;Df=8 P=0.219
0-10 Years	6(13.6%)	34(77.2%)	4(9.09%)	44(100%)	
11-20 Years	0(0%)	14(100%)	0(0%)	14(100%)	
>20 Years	0(0%)	2(100%)	0(0%)	2(100%)	
Total	6(10%)	50(83.3%)	4(6.66%)	60(100%)	

Table no.2 shows the correlation between the disability and duration of illness in the BPAD patients. Patients are divided in to three groups basing the duration of illness as 0-10 years, 11-20 years and greater than 20 years. We found that all the patients with duration of illness

between 11-20 years and above 20 years had moderate disability and severe disability is more common in patients with duration of illness less than ten years.

Table No-3 Comparison of Socio Demographic Variables With Burden In BPAD Care Givers

Variable	No Burden	Moderate Burden	Severe Burden	Total	Statistical Analysis
Age					X^2=1.71;Df=4 P=0.78
16-30 Years	0(0%)	2(33.3%)	4(66.6%)	6(100%)	
31-45 Years	0(0%)	6(37.5%)	10(62.5%0	16(100%)	
>45 Years	2(5.26%)	10(26.3%)	26(68.4%)	38(100%)	
Total	2(3.33%)	18(30%)	40(66.6%)	60(100%)	
Sex					X^2=8.56;Df=2 P=0.013
Female	0(0%)	8(21.0%)	30(78.9%)	28(100%)	
Male	2(9.9%)	10(45.5%)	10(45.5%)	22(100%)	
Total	2(3.3%)	18(30.0%)	40(66.6%)	60(100%)	
Education					X^2=11.71;Df=6 P=0.068
Illiterate	0(0%)	4(33.3%)	8(66.6%)	12(100%)	
<5 Years	0(0%)	2(11.1%)	16(88.8%)	18(100%)	
6-10 Years	2(10%)	6(30%)	12(60%)	20(100%)	
>10 Years	0(0%)	6(60%)	4(40%)	10(100%)	
Total	2(33.3%)	18(30%)	40(66.6%)	60(100%)	
Occupation					X^2=5.60;Df=2 P=0.06
Unemployed	0(0%)	6(20%)	24(80%)	30(100%)	
Employed	2(6.66%)	12(40%)	16(53.3%)	30(100%)	
Total	2(3.33%)	18(30%)	40(66.6%)	60(100%)	
Family Income					X^2=19.36;Df=6 P=0.0037 (S)
<5,000 Rs/M	2(11.11%)	4(22.2%)	12(66.6%)	18(100%)	
5,000-10,000 Rs/M	0(0%)	6(20%)	24(80%)	30(100%)	
10,000-15,000 Rs/M	0(0%)	8(80%)	2(20%)	10(100%)	
>15,000 Rs/M	0(0%)	0(0%)	2(100%)	2(100%)	
Total	2(3.33%)	18(30%)	40(66.6%)	60(100%)	
D/O/M/F					X^2=18.103;Df=6 P=0.006 (S)
<10 Years	0(0%)	4(20%)	16(80%)	20(100%)	
11-20 Years	0(0%)	10(45.45%)	12(54.5%)	22(100%)	
21-30 Years	0(0%)	4(50%)	4(50%)	8(100%)	
31-40 Years	2(20%)	0(0%)	8(80%)	10(100%)	
Total	2(3.33%)	18(30%)	40(66.6%)	60(100%)	
Domestic Voilence					X^2=7.45;Df=2 P=0.0247 (S)
Present	0(0%)	2(10%)	18(90%)	20(100%)	
Absent	2(5%)	16(40%)	22(55%)	40(100%)	
Total	2(3.33%)	18(30%)	40(66.6%)	60(100%)	

Table no.3 shows the socio demographic variables in BPAD care givers. In our study age of the care givers is divided in to three groups as 16-20 years, 31-45 years, and >46 years. The

mean age of the care givers is 36.2 ±11.64. It is found that severe burden did not vary much with the age of the care givers. When comparing the burden in relation to the gender it is found that severe burden is more commonly experienced by females than the males. The correlation between the gender and amount of burden experienced is statistically significant (p=0.013). Education level of the care giver population is sub divided into four sub groups as illiterate, people who studied <5 years, 6-10 years and greater than 10 years. It is observed that severe burden is found in people who studied less than five years when compared to other groups which can be attributed to their ignorance about the illness and poor coping mechanisms. Burden is more among unemployed care givers and in them whose family income per month is less than ten thousand rupees (p=0.003). Duration of marital life in care givers has been divided into four groups as less than 10 years, 11-20 years, 21-30 years and 31-40 years. Severe burden is seen in care givers of two groups, in those who are married by less than ten years (80%) and in them whose marital life is greater than thirty years (80%). Burden is more experienced by care givers in families where there is domestic violence and the association between domestic violence and burden experienced is statistically significant (p=0.0247).

Table No-4 Comparison of Disability In BPAD Patients With Burden In Care Givers

Variable	No Burden	Moderate Burden	Severe Burden	Total	Statistical Analysis
Disability In Patients					X^2=5.602;Df=4 P=0.23
Mild Disability	0(0%)	4(66.66%)	2(33.3%)	6(100%)	
Moderate Disability	2(4%)	12(24%)	36(72%)	50(100%)	
Severe Disability	0(0%)	2(50%)	2(50%)	4(100%)	
Total	2(3.33%)	18(30%)	40(66.6%)	60(100%)	

As shown in the table no.4, severe burden in care givers is more commonly experienced where patients have moderate disability (72%) rather than with patients having severe disability (50%).

DISCUSSION

A significant disability is found in the younger age group of patients i.e., 16-30 years. A multivariate analysis indicated that the strongest predictors of psychosocial impairment were adolescence, current mood episode, current affective symptom severity, current psychotic symptoms, and current co morbid conduct disorder. Bipolar youth in-episode were significantly more impaired than those in partial remission/recovery in every functional domain examined and were less satisfied with their functioning.[11] Disability is more in patients whose education level is more than ten years and in those who are employed. This might be because of better pre morbid functioning level prevailing in these patients and their relatively drastic decline in performance in the phase of illness.

Persistent functional disability in patients with bipolar disorder even after they cross traditional thresholds for treatment success (such as a given percentage reduction in positive symptom severity) is as a result of neurocognitive and skill deficits. Conversely, even if a patient acquires certain skills but continues to experience mild levels of core (positive and negative) and nonspecific (depressed) symptoms, changes in real-world behavior might lag or not manifest at all.[12] Patients with family income less than ten thousand rupees per month experienced more disability. Correlation between family income and disability is statistically

significant (p=0.01). Patients with less family income experienced more disability. This might be because of their poor affordability treatment. Affective disorder groups were significantly more likely to report declines in job status and income at the end of 5 year follow-up and significantly less likely to report improvements.[13] Bipolar disorder has been found to be associated with the following types of disability: increased suicidal behavior, increased health care use and costs, higher unemployment, higher dependence on public assistance, lower annual income, increased work absenteeism owing to illness, decreased work productivity, poorer overall functioning, lower quality of life and decreased life span.[14-22]

Disability is severe where the duration of illness is less than ten years. This might be because there are very few patients in our study sample with illness more than twenty years. The correlation is however not statistically significant (p=0.21). In contrast, Judd LL et al has found that patients with mood disorders experienced some degree of disability during the majority of long-term follow-up (54 to 59% of months), including 19 to 23% of months with moderate and 7 to 9% of months with severe overall impairment. Severe disability occurred a substantial percentage of time only in the specific area of work role function. BP-I patients were completely unable to carry out work role functions during 30% of assessed months, which was significantly more than for UP-MDD and BP-II patients (21% and 20%, respectively).[23]

Family members exert a crucial influence on course of illness in the major mental disorders as various parameters of family functioning are influenced. Studies have shown that family burden, defined as the emotional, social and financial stresses that the illness imposes on the family, is widely reported by care givers and is associated with less optimal clinical and psycho social outcome.[24-27] Studies on Bipolar Affective illness suggest that family members of persons with this illness experience considerable subjective distress as well.[28, 29]

The correlation between the gender and amount of burden experienced is statistically significant (p=0.013). More burden in female care givers may be due to the fact that majority of the care givers are the spouses of the patients and therefore in a family where the patient is male the financial parameter of the family functioning is significantly impaired. Severe burden in less educated population can be attributed to their ignorance about the illness and poor coping mechanisms. Statistically significant burden is there among unemployed and in those with a monthly income less than ten thousand rupees (p=0.003). This can be explained in terms of poor affordability and poor accessibility to health care services in unemployed population. In a study conducted by Wolf N et al [30] on BPAD patients it is found that financial burden appears to be a unique dimension that is significantly inter correlated with psychological measures in the care giving population.

Severe burden is seen in care givers of two groups, in those who are married by less than ten years and in them whose marital life is greater than thirty years. This is an interesting finding we observed in our study and the correlation is statistically significant. We could not find any previous studies with similar finding. Presence of domestic violence in the family has contributed to a significant burden. Caregivers reported significant difficulties in their relationships with the patient when he/she was unwell, with considerable impact on their own employment, finances, legal matters, co-parenting and other social relationships. Violence was a particular worry for partner/parent caregivers of both male and female patients when the patient was manic.[31] Severe burden is present in families where patients experienced moderate disability rather than severe disability. This could be because of the established coping mechanisms in care givers where the illness has been more chronic and disabling.

This is differing with the finding of previous studies conducted by Perlick et al[32] according to which caregivers of patients with bipolar illness experience a high burden where patients have severe disability.

SUMMARY AND CONCLUSIONS

1. The mean age of the patients is 33.97 ± 9.8.
2. Severe disability is present in younger patients than the older ones and this difference is statistically significant.
3. Disability of the patients didn't vary much with the gender, level of education or employment status.
4. Disability is more in urban population, in extended families.
5. The correlation between family income and disability is statistically significant (p=0.01).
6. Disability is more severe in patients with duration of illness less than ten years.
7. The mean age of the care givers is 36.2 ±11.64.
8. Significant amount of burden is experienced by female caregivers when compared to males.
9. Poor care givers with a monthly income less than ten thousand rupees experienced significant burden.
10. Burden is more experienced by care givers in families where there is domestic violence and the association between domestic violence and burden experienced is statistically significant.

Limitations

1. The time bound nature of the study dictated a small sample size.
2. All the patients with alcohol dependence syndrome were male and all their care givers were females of whom most of them are spouses of the patients.
3. Restricted nature of sample means that the findings are not readily applicable to other population.
4. Assessment was cross-sectional and non-blind.
5. Those alcohol dependence patients and bipolar patients who did not/never attend OPD were obviously out of study.
6. On direct enquiry, there could be chances of wrong information.
7. Several factors such as coping, expressed emotions etc were not assessed.

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Conflict of Interest
The authors carefully declare this paper to bear not conflict of interests

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