Anxiety, Depression and Burden in Caregivers of Psychotic Patients on Treatment

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Abstract:
BACKGROUND: Psychotic disorders are a major group in psychiatric disorders causing psychological turmoil to both family and society. Bipolar disorder and schizophrenia comprise the two major groups of psychotic disorders. These disorders are mostly chronic, requiring long term treatment along with family and social support. The caregivers of these patients play a pivotal role in supporting the patients medically, emotionally and financially. So, there is a need to identify burden and emotional aspects in the caregivers of psychotic patients.
AIMS: 1. To assess the burden perceived by caregivers of psychotic patients (bipolar disorder and schizophrenia) receiving medical treatment.  
2. To assess the anxiety, stress and depression in the caregivers of psychotic patients.  
3. To compare the burden, anxiety, stress, depression between caregivers of patients suffering from bipolar disorder and schizophrenia.
METHODS: The Caregivers of the patients suffering from bipolar disorder and schizophrenia diagnosed as per ICD-10 are assessed by Burden Assessment Scale (BAS) and Depression Anxiety Stress Scale (DASS). The results of both the groups are compared.
RESULTS: Caregivers of 96 psychotic patients had mean scores of burden assessment 74.34(S.D 10.92), anxiety 3.52(4.75), stress 7.97 (7.08) depression 14.27(10.11). Bipolar disorder group had burden assessment score of 72.02(S.D10.69), anxiety score of 3.55(S.D 4.9), stress score of 10.91(S.D 8.2) and depression score of 14.86(S.D 9.74). Caregivers of schizophrenia had mean scores of burden assessment 76.41(S.D 10.79), anxiety 3.49(S.D 4.66), stress score of 5.39(S.D 4.64) and depression scores of 13.7(S.D 10.52).
CONCLUSIONS: Caregivers of both schizophrenia as well as bipolar disorder group scored high scores on burden assessment scale suggesting burden load in caring for the patients. Caregivers of schizophrenia group scored more in burden scores and bipolar disorder group scored more in stress scale of DASS. Both groups scored on the criteria for mild depression of DASS.
KEY MESSAGE: Caregiver’s burden, their anxiety and depressive symptoms must be addressed along with the pharmacological treatment of the patients with psychotic disorders. Caregivers of bipolar disorders patients also perceive burden.

Keywords: Anxiety, stress, depression, burden, psychotic disorders, caregivers
1. Introduction
Focus on the role of family in the life of a person with mental illness has been dual. Where earlier the focus had been on the possible etiological role of the family in mental illness, there now seems to be a paradigm shift and family now is being perceived as a “reactor” to mental illness of a member.\(^{(i)}\)
With increasing change in mental health policies to integrate the persons with mental illness in the community, family care giver has now become a major stake holder in overall management\(^{(ii)}\).
Family is defined as a group of individuals who live together during important phases of their life time and are bound to each other by biological and /or social and psychological relationship.\(^{(iii)}\)
The family caregiver is often subject to multiple sources of stress. The family caregivers not only have to manage the behavioural disturbances of the ill family member but are often themselves a target of the patient’s aggression. The financial burden is also manifold. They not only have to meet financial needs and cost of treatment of the patients but may have to leave their own jobs to look after them. Social and leisure activities may also have to be curtailed. These multiple sources of stress may take a toll on the physical and mental health of the caregivers. This stress of care giving has been labelled as caregiver burden in the literature.\(^{(iv)}\)
World Health Organization has defined ‘care giver burden’ as the “the emotional, physical, financial demands and responsibilities of an individual’s illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system.”\(^{(v)}\)
Burden can be differentiated into objective and subjective dimensions of burden. Objective burden is defined as the concrete and observable costs to the family that result from the disease, such as financial expenditures and disruption of everyday life, where as subjective burden refers to individuals own assessment of his or her impairments and the extent to which he or she perceives the situation as burdensome.\(^{(vi)}\)
The caregivers caring for their patient with mental illness feel stressed, anxious and low. Since the illness tends to be chronic and demanding it may lead to burnout and emotional exhaustion\(^{(vii)}\). The burden can further affect the health related quality of life\(^{(viii)}\). This burden can lead to impaired coping mechanisms in care givers like denial by parents, resignation\(^{(ix)}\) by relatives and negative distraction strategies by spouses\(^{(x)}\).
Apart from psychotic disorders care givers of other mental and physical illnesses also perceive burden. For instance Caregivers of Alzheimer’s reported anxiety, depression and burden\(^{(xi-xiii)}\) whereas caregivers of Post traumatic stress disorder reported burden\(^{(xiv-xv)}\) and care givers of cancer patients of stress\(^{(xvi)}\). Studies have found that the caregiver burden of psychiatric illness were significantly higher than that of chronic medical illness\(^{(xvii)}\). A number of factors determine the caregiver burden. These include characteristics of the person with mental illness, characteristics of caregivers, and relation between them, time spent by the caregiver with patient and nature and severity of illness.\(^{(xviii)}\)
There are very few studies which have actually compared the family burden among different groups of psychiatric patients\(^{(xvi-xviii)}\). Studies have concentrated on schizophrenia and research data pertaining to family burden in affective disorders is limited. Considering the important role the caregiver plays in the life of a person with mental illness, any negative experiences may affect their ability to care for the patients and therefore should be given adequate attention. A better understanding of the effects of mental disorders on caregivers of patients will enable us to extend help and support tailored to their needs.\(^{(xviii)}\)
The present study is an attempt to study the stress, anxiety, depression and burden in the caregivers of patients suffering from bipolar disorder and schizophrenia, on treatment with psychotropic medication.

2. Materials and Methods
This study was conducted in inpatient ward of Institute of mental health, Hyderabad. The study design is instrument rated and head to head comparison.

2.1. Selection Criteria
51 primary care givers of schizophrenia patients and 45 primary caregivers of bipolar disorder were included in the study. Schizophrenia and bipolar disorder were diagnosed according to ICD-10\(^{(xiv-xvii)}\) and were of at least two years duration. To be included in the study the care givers should have been above 18 years of age, relatives of the patient, living with the patient in the same environment for at least 12 months and directly involved in the care of the patient i.e. emotionally, financially. Care givers of patients with schizophrenia and bipolar disorders with comorbid conditions like mental retardation, physical illnesses, substance abuse and personality disorders were excluded from the study. Caregivers having psychiatric disorder currently or in the past and having physical illness were excluded from the study.
The tools used for the study were burden assessment scale (BAS) (40 items) and depression anxiety and stress scale (DASS).

3. Description of Tools

3.1. Burden Assessment Scale\(^{(xv-xvii)}\)
This was developed by Thara et al at the Schizophrenia Research Foundation (SCARF). This is a semi quantitative, 40 item scale measuring 9 different areas of care givers burden both objective and subjective. Each item is rated on a 3 point scale. Scores range from 40 to 120, with lower scores indicating lower burden.
3.2. Depression anxiety and stress scale (DASS)\(^{(xxi)}\)

The DASS is a 42 item questionnaire designed to measure anxiety, stress and depression. Each of the 3 scales contains 14 items each. Respondents are asked to use 4 point severity scales to rate the extent to which they have experienced each state over the past week. Scoring for depression (0-9) normal, (10-13) mild, (14-20) moderate, (21-27) severe, (28+) extremely severe. Anxiety (0-7) normal, (8-9) mild, (10-14) moderate, (15-19) severe, (20+) extremely severe. Stress (0-14) normal, (15-18) mild, (19-25) moderate, (26-33) severe, (34+) extremely severe.

The statistical analysis was done using descriptive statistics, analytical statistics by t test.

4. Results

The study group consisted of 96 subjects, 45 caregivers of the bipolar group and 51 of the schizophrenia group. Among caregivers of 96 patients, mean burden score was 74.34 (S.D 10.92), anxiety score was 3.53 (S.D 7.45) stress score was 7.97 (S.D 7) and depression score was 14.27 (S.D 10.11) (table 2).

<table>
<thead>
<tr>
<th></th>
<th>Bipolar group (MEAN and S.D)</th>
<th>Schizophrenia group (MEAN and S.D)</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>MALE patients group</td>
<td>FEMALE patient group</td>
</tr>
<tr>
<td><strong>N</strong></td>
<td>28</td>
<td>17</td>
</tr>
<tr>
<td><strong>Age Of Informant</strong></td>
<td>44.14(SE 10.98)</td>
<td>40.41(SE 9.48)</td>
</tr>
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<td><strong>Age Of Patient</strong></td>
<td>28.6(SE 6.11)</td>
<td>30.29(SE 8.62)</td>
</tr>
<tr>
<td><strong>Duration Of Illness In Years</strong></td>
<td>5.32</td>
<td>3.5</td>
</tr>
<tr>
<td><strong>Monthly Income Of Patient In Rupees</strong></td>
<td>6946.42</td>
<td>3452.9</td>
</tr>
<tr>
<td><strong>Patient Education In Class</strong></td>
<td>10.64(SE 3.37)</td>
<td>5.7(SE 2.54)</td>
</tr>
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<td><strong>Education Of Informant In Class</strong></td>
<td>6.89(SE 4.23)</td>
<td>1.29(SE 1.15)</td>
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</table>

Table 1: Comparison between bipolar and schizophrenia group

Schizophrenia group consisted of 35 male patients and 16 female patients and their caregivers. The mean age of males was 41.14 years and the mean duration of illness was 6.82 years. (table 1) The burden assessment scale mean value was 77.68. DASS mean anxiety score was 3.65, stress was 5.51 and depression was 15.34. The mean age of females in this group was 32.62 years and the mean duration of illness was 5.2 years. Burden assessment mean value was 73.6, DASS mean anxiety score was 3.1, stress was 5.12 and depression score was 10.12.

Bipolar group consisted of 28 male patients and 17 female patients. The mean age of males was 28.6 and the duration of illness was 5.3 years. The mean scores of burden assessment scale was 73.9, and DASS anxiety score was 4.9, stress mean score was 13.14 and depression mean score was 15.53. Females had a mean age of 30.29 years, with mean duration of illness of 3.86 years. The mean score of burden assessment was 68.7, DASS anxiety was 1.29, stress score was 7.23 and depression score was 13.76 (table 2).

<table>
<thead>
<tr>
<th></th>
<th>Bipolar group (MEAN and S.D)</th>
<th>Schizophrenia group (MEAN and S.D)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>MALE patients</td>
<td>FEMALE patients</td>
</tr>
<tr>
<td><strong>Psychotic patients</strong></td>
<td>74.34(SE 10.92)</td>
<td>72.96(SE 11.25)</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>3.53(SE 4.75)</td>
<td>4.92(SE 5.75)</td>
</tr>
<tr>
<td><strong>Stress</strong></td>
<td>7.97(SE 7.08)</td>
<td>13.14(SE 9.52)</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>14.27(SE 10.11)</td>
<td>15.53(SE 7.63)</td>
</tr>
</tbody>
</table>

Table 2: burden, DASS scores of total psychotic group and individual groups

The caregivers of bipolar group scored the mean burden value of 72.02 compared to schizophrenia mean of 76.41 with probability of 0.04. DASS anxiety scores were almost similar with scores 3.55 in bipolar group and 3.49 in schizophrenia group with probability of 0.94. The stress score of bipolar group was comparatively higher(Figure 1) with mean value of 10.91 compared to 5.39 in schizophrenia group with probability of 0.0016. The caregivers of bipolar disorder scored depression score of 14.86 compared to 13.7 in schizophrenia group with probability of 0.57. Both the groups scored above 9 on depression scale suggesting mild depression as per DASS Scoring.
Among 96 patients males scored burden of 76.03 compared to 71.12 of females. DASS scores of anxiety, stress and depression were 4.22, 8.9, 15.42 in males and in females the scores were 2.18, 6.21, 12.06 respectively. (table 3)

<table>
<thead>
<tr>
<th></th>
<th>Male patients (MEAN and S.D)</th>
<th>Female patients (MEAN and S.D)</th>
<th>t test probability</th>
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</thead>
<tbody>
<tr>
<td>BURDEN</td>
<td>76.03 (S.D 11.3)</td>
<td>71.12 (S.D 9.5)</td>
<td>0.03</td>
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<tr>
<td>ANXIETY</td>
<td>4.22 (S.D 5.38)</td>
<td>2.18 (S.D 2.84)</td>
<td>0.04</td>
</tr>
<tr>
<td>STRESS</td>
<td>8.9 (S.D 8.18)</td>
<td>6.21 (S.D 3.81)</td>
<td>0.07</td>
</tr>
<tr>
<td>DEPRESSION</td>
<td>15.42 (S.D 9.6)</td>
<td>12.06 (S.D 10.82)</td>
<td>0.13</td>
</tr>
</tbody>
</table>

5. Discussion
In our study, we have assessed and compared the stress, anxiety and depression and burden in caregivers of patients suffering from major psychotic disorders namely bipolar disorder and schizophrenia receiving medical treatment. Earlier studies have not focussed selectively on patients receiving treatment. We have assessed caregivers of patients receiving treatment and already hospitalized to exclude compliance issues.

The past studies have assessed burden in schizophrenia and comparatively neglected bipolar disorders. So we have assessed and compared the burden of care in both groups. There were comparatively less Indian studies for assessing burden, depression and anxiety in caregivers.

We have excluded the care givers having past or current psychiatric disorders because patients already having psychiatric disorders tend to experience recurrence due to stress diathesis interaction. 

In this study we have excluded caregivers reported to have medical illness because the impaired physical health can affect their psychological well being and increase the risk. We also excluded younger age caregivers (below 18) because they are not able to understand the concept of care giving, nature of illness, medication issues and tend to report more stress and increased burden.

There is increase in the burden and anxiety scores of caregivers of male patients (table 3). This may be explained by the fact that in the Indian context the breadwinners are males and their illness may impact the family more, both financially and occupationally. In our results the caregivers of both the disorders have experienced more burden, more levels of depression. The mean age of caregivers of males patients of schizophrenia group was 31.2 years and bipolar 28.6 years and the older age group in schizophrenia may be due to chronic nature of illness.

In our study there is greater burden in schizophrenia compared to bipolar disorder. This increased burden score could be due to continuous illness pattern and less insight in schizophrenia. The stress levels were comparatively high in caregivers of bipolar patients. This can be due to the acute nature of the episodes in bipolar disorder, leading to difficulty in managing aggression and increased activity levels. Since there is an acute attack after a period of normalcy, the caregivers might experience stress due to apprehension of repeated future episodes.

The increased perception of stress could also be due to the caregiver’s abilities to manage stressors, the increased reaction to the stressors and ability to modulate their impact. Caregivers loss of family life and their occupational interference can further increase the stress levels. The stressors experienced in their roles and activities apart from that of care giving and the intrapsychic strains involving the diminishment of self concepts may increases stress levels.
The high depression levels of DASS score in both the groups could be due to ideas of hopelessness in managing psychotic illness, grief associated with role loss in family, disruption of family interactions and financial and occupational difficulties in caring for the patients. The increase in the depression scores could be due to the inter relation issues between the caregiver and the patient (xv). Care of patients for extended period of time without leisure and staying with patient alone most of the time may also make them depressed (xxxv).

So there is a need for caregiver support programs to address burden, anxiety and depression issues (xxviii). Good social and family support can decrease the stress levels. Yoga can be advised to reduce depressive and anxiety symptoms (xxviii,xxxv). Family therapy (xxxv) for addressing psychological symptoms of caregiver could be one of the modalities of treatment. Cognitive behaviour interventions can be advised for caregivers having depression and anxiety (xxviii,xxxv). Coping strategies like emotion focussing can be advised for caregivers as it seems to protect from anxiety (xxviii,xxxv). Coping mechanisms such as problem solving can decrease the burden of illness on caregivers, (xxxv) Individual psychotherapy can also be advised (xxxv). Burden and distress in family may be reduced by conducting regular group meetings (xxviii). It should be kept in mind however that psycho education can sometimes be stressful to the caregivers as it increases the awareness of the severity of illness and its future course (xxxv).

Psychological symptoms of caregivers of both the illness are often neglected by the psychiatrists and other mental health professionals. There is a need to address their suffering and provide appropriate psycho education, family interventions and social support through self-help groups, non-governmental organisations and government policies, thereby leading to better care of both the patients and their caregivers.

6. Limitations

1. This study was done in in- patient ward and is cross sectional in nature
2. Severity of illness is not compared.

7. Future directions

1. Community based studies for assessing caregiver’s burden
2. Follow up of caregivers after giving psychological treatment and continuous assessment and support.

8. References


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