

Case Series

Caregiving of Patients Living with Mental Illness-An experience from Rural Community

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Abstract

Introduction: People living in rural areas are often faced with multiple, complex, and seemingly insurmountable barriers to receiving appropriate treatment for mental health problems. The study aimed to assess the severity and disability due to illness of Patients Living with Mental Illness residing in rural area and family burden experienced by their caregivers.

Methods: A Case Series (cross-sectional) was carried out by Psychiatrists and Public Health Experts of a Medical College at an outreach Mental Health Clinic (dispensary). 36 patients and their caregivers were interviewed and assessed. A semi structured questionnaire was used for demographic profile and history of the illness. Diagnosis of Schizophrenia was established using DSM V. The tools used were; Family Burden Interview Schedule, Global assessment of Functioning and Indian Disability evaluation and assessment scale. Descriptive statistics and Pearson's correlation coefficient were utilized for analysis.

Results: Almost 97.2% of the caregivers had experienced some burden (moderate or severe) in at least one item of FBIS, especially; financial burden, disruption of routine family activities & family interaction and disruption of family leisure. The Pearson's correlation coefficient between GAF scores and FBIS scores showed a strong negative correlation.

Conclusion/Recommendation: Strengthening of Community Based Rehabilitation that could lessen the burden of the family and society is the need of the hour to improve quality of life of PLWMI.

Keywords: Burden of Care; mental disability; patients living with mental illness; rural area.

Introduction

Mental health is one of the critical health requirements that society needs to address in the present century. Around 14% of the global disease burden is caused by mental disorders and one of the 10 leading causes of disability in Asia is mental illness [1]. It is estimated that 1 in every 4 families has a member suffering from a mental health disorder [2]. People with serious mental health problems die prematurely because of preventable physical conditions, as early as two decades [3]. The potential lack of equal involvement in family life, normal social networks and sustainable jobs, as well as decreased chances of rehabilitation, may be impeded by their ability to access care and may influence the form of treatment and quality of help obtained [4].

Very often, the family has to face significant and serious physical and psychological burden, as the family is a part of the care system for a person with chronic mental illness. In such conditions, the family has to provide extra care to the person than usual. It involves taking care of personal hygiene of patients, emotional support such as listening, counseling, and companionship, and informational caring such as learning how to change the living environment of the patients. Various studies have shown a high degree of subjective and objective burden on family members [5, 6, 7]. People living in rural areas are often faced with multiple, complex, and seemingly insurmountable barriers to receiving appropriate treatment for mental health problems. The study aimed to assess the severity and disability due to illness of Patients Living with Mental Illness residing in rural area and family burden experienced by their caregivers.

Methods

Study design & site: A Case Series (cross-sectional) was carried out by Psychiatrists and Public Health Experts of a Medical College at an out-

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reach Mental Health Clinic (dispensary).

Sample Size: 36 patients and their caregivers were interviewed and assessed.

Inclusion criteria: Patients who were already diagnosed as suffering from Schizophrenia, aged 18-65 years, had come with a caregiver and gave informed verbal consent were included in the study after establishing the diagnosis of Schizophrenia as per Diagnostic and Statistical Manual of Mental Disorders (DSM) V [8]. Privacy was maintained throughout the course of interview. Only those caregivers were selected who were an adult relative, were staying with the patient in the same household and responsible for care of the patient

Tools used: A semi structured questionnaire was used for demographic profile and history of the illness. Diagnosis of Schizophrenia was established using DSM V. The family burden was assessed using Family Burden Interview Schedule (FBIS) developed by Pai and R. L. Kapoor in 1981 [9]. Severity of the illness was gauged by using GAF (Global assessment of Functioning) [10] and disability due to illness was assessed using IDEAS (Indian Disability evaluation and assessment scale) [11]. The doctors who took part in the study were trained in the use of FBIS, GAF and IDEAS before commencement of the study. Descriptive statistics and Pearson's correlation coefficient were utilized for analysis.

Results

The mean age of the 36 patients assessed was 37 years (range 16 to 65 years). There were 19 (52.8%) females and 17 (47.2%) males. All the patients were currently residing in rural area. Twenty (55.6%) patients had received at least some level of schooling. All the patients were Hindus. Seven patients were farmer by occupation, 19 were housewives, six were currently unemployed due to illness, two were working as semi-skilled worker and other two were students. Twenty-three were married, eight were unmarried, three were separated, one was divorced and one other was widow.

Mean duration of illness was 49.44 months i.e. almost four years (range of 6 to 144 months). Average time taken from onset of illness to first consultation with Psychiatrist was approximately seven weeks. Four patients were taken to Psychiatrist immediately after onset of illness and one patient was taken for consultation after one week of onset of illness. There were at least two patients who went for Psychiatric consultation for the first time about five years after onset of illness and at least five patients went to Psychiatrist almost a year after onset of illness. No significant difference was observed between male and female patients.

1. Patient distribution by GAF scores

| Sr. No. | GAF score | Number of patients |
|---------|-----------|--------------------|
| | 0-20 | 4 |
| | 21-40 | 11 |
| | 41-60 | 6 |
| | 61-80 | 7 |
| | >80 | 8 |

2. Severity of burden due to illness for six areas of FBIS

| | Area | Mean sub score of FBIS | Number of caregiver with moderate or severe burden* N (%) |
|---|---|------------------------|---|
| A | Financial Burden | 3.8 | 33 (91.7) |
| B | Disruption of routine family activities | 4 | 32 (88.9) |
| C | Disruption of family leisure | 2.5 | 31 (86.1) |
| D | Disruption of family interaction | 3.7 | 32 (88.9) |
| E | Effect on physical health of others | 0.67 | 14 (38.9) |
| F | Effect on mental health of others | 0.78 | 23 (63.9) |

*Number of caregivers with moderate or severe burden in at least one item of the burden within the area.

Among the various areas of burden, financial burden was experienced by 91.7% of caregivers, disruption of routine family activities and family interaction was reported by 88.9% of caregivers, while disruption of family leisure was reported by 86.1%, which shows that burden in these areas are very high. Effect on mental health was also reported by 63.9% caregivers. Though the effect on physical health was reported by only 38.9% caregivers, the real number could be high as it could be difficult for them to gauge the indirect effects of stress on their health. The mean total score of FBIS in this study was 15.44. Out of the 36 caregivers 35 (97.2%) reported some burden (moderate or severe) in at least one item of FBIS

1. Overall subjective burden of the family.

| Sr. No. | Severity of burden | Number of families |
|---------|---------------------|--------------------|
| 1 | 2 (Severe burden) | 10 |
| 2 | 1 (Moderate burden) | 21 |
| 3 | 0 (No burden) | 5 |

At least 10 caregivers reported of severe (2) overall burden in the family due to the illness, while 21 reported of moderate (1) burden and 5 reported of no burden (0).

2. Correlation between GAF scores and FBIS scores.

| Total FBIS score | GAF Score |
|---------------------|-----------|
| Pearson Correlation | -0.641 |
| P-value | <0.001 |
| N | 36 |

The Pearson's correlation coefficient between GAF scores and FBIS scores was; $r = -0.641$ which represents a strong negative correlation.

3. Disability due to illness as per IDEAS

| Sr. No. | Disability (in percentage) | Number of patients |
|---------|----------------------------|--------------------|
| 1 | <40 | 16 |
| 2 | 40-70 | 16 |
| 3 | 71-99 | 4 |

All the patients were having at least mild disability but none of the families had availed government welfare facilities provided to patients with disability due to mental illness and none of them had been certified for their disability.

Conclusion

This study found that almost 97.2% of the caregivers had experienced some burden (moderate or severe) in at least one item of FBIS, especially; financial burden, disruption of routine family activities& family interaction and disruption of family leisure. The Pearson's correlation coefficient between GAF scores and FBIS scores showed a strong nega-

tive correlation. Despite the fact the patients were suffering from a disabling disorder none of them had undergone disability certification.

Recommendations:

There is a need to ensure continued care of PLWMI. Default action through family member or friend or link workers could be channelized. Mental health professionals need to be aware and provide support to the family members of Schizophrenia patients. Strengthening of Community Based Rehabilitation that could lessen the burden of the family and society is the need of the hour to improve quality of life of PLWMI. All PLWMI should undergo disability certification which would help in reducing the burden of caregivers.

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