

Burden of Caregivers in Severe Mental Illness: A Cross Sectional Study

***Mukesh Chand Daderwal¹, Ms. Sanya Badera², Dr. Priyanka Kumari³**

¹MD psychiatry

Senior Resident, Dept of Psychiatry,
SMS Medical college and Hospital, Jaipur, Rajasthan
Email- daderwalmukesh@gmail.com

²B.Sc. (H) Psychology

IIS university, Jaipur

Email: baderasanya2001@gmail.com

³Assistant professor in dept of psychology
Govt PG College for Women, Rohtak, Haryana
Email: priyanka.sheoran27@gmail.com

***Corresponding author**

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Abstract

Long-term mental illnesses like schizophrenia, bipolar disorder and substance use disorder often impose a burden on the patient as well as on the primary caregivers to the patient. There are several instruments constructed to measure the burden inflicted on the patient's family or caregiver. One of these instruments used to measure caregiver's burden is Involvement Evaluation Questionnaire (IEQ). The IEQ is a 31-item questionnaire which is completed by the caregiver. [6] It contains 27 questions which are divided into 4 subscales: tension (nine items), supervision (six items), worrying (six items) and urging (eight items). Two items appear in more than one domain. The items are scored on a 5-point Likert scale (never, sometimes, regularly, often and [almost] always).

The questionnaire was administered to forty-five primary caregivers of patients with schizophrenia, bipolar disorder or substance use disorder. The caregivers were aged between 18-70 years and the duration of the illness was more than 3 months.

The patients and caregivers were both predominantly male. When the IEQ was analyzed, the mean score was 52.5 (17.6). The mean of the GHQ was 5.19 (2.83).

The majority of caregivers surveyed were male and family members. 33.3% of the caregivers were parents of the patient. More than 86% of the caregivers provided help for more than 32h with the patient.

Introduction

Schizophrenia involves a range of cognitive, behavioural, and emotional symptoms. According to the DSM-5, the lifetime prevalence of schizophrenia is approximately 0.3% to 0.7%. Psychotic features of the disorder typically emerge between the mid-teens and mid-30s, with the peak age of onset of the first psychotic episode in the early to mid-20s for males and late twenties for females. Schizophrenia is associated with social and occupational dysfunction. Completing education and maintaining employment are negatively impacted by symptoms of the illness, and most individuals diagnosed with schizophrenia are employed at a lower level than their parents. Many have few or limited social relationships outside of their immediate family. [1]

Bipolar disorders are described by the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as a group of brain disorders that cause extreme fluctuation in a person's mood, energy, and ability to function. [1]

People who live with bipolar disorder experience periods of great excitement, overactivity, delusions, and euphoria (known as mania) and other periods of feeling sad and hopeless (known as depression).

Family members are affected by every episode of this illness as well as scared of a possible relapse when the disorder is stabilised.

Substance addiction (or drug addiction) is a neuropsychiatric disorder characterised by a recurring desire to continue taking the drug despite harmful consequences. [9] People usually progress from experimentation to occasional use and then to heavy use and sometimes to a substance use disorder. This progression is complex and only partially understood. The process depends on interactions between the drug, genetics, and environment. [12]

Several researchers found that families of individuals with substance use disorders experience economic burden, social isolation, psychological strain, shame, embarrassment, guilt, self-blame, (marital problems, and threats to their physical health).

Caregiver is the person who provides care to those who need supervision or assistance in illness or disability. They may provide the care in the home, in a hospital, or in an institution. Although caregivers include trained medical, nursing, and other health personnel, the concept also refers to parents, spouses, or other family members, friends, members of the clergy, teachers, social workers, fellow patients.

Difficulties in mental health affect several million people worldwide. The importance and contribution of family carers in promoting positive wellbeing and improved outcomes for those with lived experiences of mental ill health is frequently acknowledged by health providers, policy makers and governments. [9]

Unlike professional caregivers such as physicians and nurses, informal caregivers, typically family members or friends, provide care to individuals with a variety of conditions including schizophrenia, dementia, and cancer. This experience is commonly perceived as a chronic stressor, and caregivers often experience negative psychological, behavioural, and physiological effects on their daily lives and health. [3]

The caregiver's burden is complex and complicated by multiple competing priorities. Because caregivers are often faced with multiple concurrent stressful events and extended, unrelenting stress, they may experience negative health effects, mediated in part by immune and autonomic dysregulation. [4]

As we look towards the modern day, contemporary findings from large scale population survey data highlight that carers, compared to the general population, report higher levels of common mental disorders, and with a notable deterioration in levels of functioning and wellbeing among those providing care of 10 hours per week or more (e.g. Smith et al., 2014). Reports of fatigue, suicidal thinking, psychological distress, social isolation, sleep dysfunction and poor quality of life are all significantly elevated in carer groups. Family carers have also reported feelings of "burnout", reports of loss, not dissimilar to reactions following a bereavement, and trauma.[15]

To analyse the amount of stress and burden the primary caregivers are facing of patients suffering from schizophrenia, bipolar disorder and substance use disorder, we surveyed with

the help of Involvement Evaluation Questionnaire. This questionnaire has four subscales: tension, supervision, worrying and urging.

Setting

A tertiary care Centre specially for patients with mental disorders including both In Patient and Out Patient Department

Methods

Participants

The 81-item Involvement Evaluation Questionnaire was administered to 45 primary caregivers of patients with severe mental illnesses (Schizophrenia, Bipolar Disorder and Substance use disorder). All the patients were diagnosed according to the ICD-10 criteria. In addition, they had to be aged 18 to 70 years, had an illness duration of > 3 months. Only those judged to be intimately involved in the patient's care were included. This involved looking after the patient's daily needs, supervising medications, bringing the patient to the hospital, staying with the patient during hospitalization, and liaising with the hospital staff.

Instruments

The Involvement Evaluation Questionnaire was used with General Health Questionnaire. The Involvement Evaluation Questionnaire is self-report questionnaire with 31 items and has been developed to measure care- givers' worries, coping and emotional burden as a consequence of mental illness of patients.

The Involvement Evaluation Questionnaire is scored on a 5-point Likert scale (never, sometimes, regularly, often, [almost] always). The questions concern a period of four weeks prior to the assessment. It takes about 20 minutes to complete the Involvement Evaluation Questionnaire.

Two items contribute to two subscales. The Involvement Evaluation Questionnaire has a sum score based on 27 items and comprises four subscales:

1. Tension (9 items) refers to a possibly strained interpersonal atmosphere.
2. Supervision (6 items) by caregivers of patients' medicine intake, sleep, dangerous behaviours, etc.
3. Worrying (6 items), which covers painful interpersonal cognitions, for instance on patient's safety, health and health care.
4. Urging (8 items), which refers to activities such as stimulating the patient to take care of himself, eat appropriately and undertake sufficient activities.

The 12 item version of the General Health Questionnaire is a widely used self-report screening instrument for psychological health in general health care. The General Health Questionnaire is used as case-detector for mental health problems.

Table 1:

Caregiver Demographics and characteristics

	Caregiver (n=45)
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Mean age (SD)		40.95 (16.2)
Gender (n, % male)		28 (62.2%)
Relationship to patient	Partner/Spouse	11 (24.4%)
	Parent	15 (33.3%)
	Offspring	7 (15.5%)
	Sibling	3 (6.6%)
	Other family member	7 (15.5%)
	Other	2 (4.4%)
Mean hours of care provided a week (SD) (h)	More than 32h a week	39 (86.6%)
	9-32h a week	2 (4.4%)

Results

45 caregivers of patients with acquired mental disorders were included in the trial. All caregivers were willing to participate. The caregivers were predominantly male (62.22%; n=28), their mean age was 40.9 (16.2) years, and most caregivers (33.33%; n=15) were parents. Fifteen (33.33%) patients were diagnosed with Schizophrenia; fifteen (33.33%), bipolar disorder and fifteen (33.33%) of substance use disorder. Patients were predominantly male (64.44%; n=29) and their mean age was 36.7 (14.5) years.

The mean of the General Health Questionnaire was 5.19 (2.83). More than 73% of the caregivers felt that they are constantly under strain; 55.5% have lost sleep because of worry of the patient's illness; and, 80% have been feeling unhappy or depressed.

When the IEQ was analysed, the caregivers scored highest for 'worrying' (52.37%), followed by 'tension' (47.2%) and 'urging' (40.75%). The 'supervision' (26.75%) domain scored the lowest of the maximum score.

Table 2:

Patient Demographics and characteristics

		Patient (n=45)
Mean age (SD)		36.8 (14.5)
Gender (n, % male)		29 (64.4%)
	Schizophrenia	15 (33.3%)

Diagnosis	Bipolar Disorder	15 (33.3%)
	Substance use disorder	15 (33.3%)
Mean years since diagnosis (SD)		9 (9.24)

Table 3:

Involvement Evaluation Questionnaire:

Subscale	'n' items	Mean	SD
Tension	9	17.5	7.7
Supervision	6	6.4	3.9
Worrying	6	12.5	5.7
Urging	8	13.0	7.7
Total IEQ	27	52.5	17.6

Table 4:

General Health Questionnaire:

GHQ	'n' items	Mean	SD
	12	5.1	2.8

Discussion

All schizophrenia, bipolar disorder and substance use disorder are chronic conditions that have a direct and notable impact on the family and friends of those affected. The majority of caregivers surveyed in this real-world survey were male and family members. More than 86% of the caregivers provided help for at least 32h a week.

Existing studies have shown high intensity caregiving to have a negative impact on health. Distress, anxiety and mood symptoms have been previously noted amongst informal caregivers of patients with bipolar disorder, and carers themselves are a high-risk group for developing psychiatric disorders.[11] A prospective study identified double the amount of psychological distress in high intensity caregivers versus non-caregivers and of note, distress was higher in females and those caring for a partner or spouse. [2] However, similarities must be drawn with caution given the distinctly different patient populations included in this survey and the prospective study above, which is likely to impact burden.

Research on the consequences of mental illness for patients' relatives can be divided into three distinctive periods. First, starting in the 1950s, researchers described in detail all the different consequences for family members. They paid particular attention to negative aspects. In the second period, starting in the early 1970s, family burden became one of the outcome measures in mental health service evaluation. Instruments were developed and used in studies that compared community approaches with the more classical approaches. In the

third period, beginning in the early 1980s, interventions or treatment programmes with a psycho-educational approach which aimed at a reduction of family burden, family stress or expressed emotion became the central point of interest. Recently, a fourth period has started with the emphasis on relatives' needs, perceptions and attributions, coping style and mental health. [8], [13]

Caregivers of persons/patients with bipolar disorder can benefit from psychoeducational interventions designed to provide information, support and stress management skill building. [7]

It has been demonstrated in randomized controlled trials that a psychoeducational approach can improve outcomes for both patients and families. The ways of intervention have to be investigated with further studies but what is sure at this time is that professionals and non-professional caregivers should work together to support people with affective disorder more efficiently. [11] Perlick et al suggested that caregivers treated with a psychoeducational and cognitive-behavioural approach in the family focused treatment health promoting intervention condition reported a significant reduction in depressive symptoms and improvement in health behaviours when compared to caregivers who received education alone. They also experienced significant reductions in subjective burden associated with the patient's symptoms and role dysfunction during the course of treatment.

In a research for coping among caregivers of patients with bipolar disorder, caregivers used a wide variety of coping strategies, both problem and emotion-focused. In bipolar disorder, demographic parameters, illness duration, levels of dysfunction, burden and social support, and appraisal by caregivers demonstrated significant associations with coping styles of caregivers. [14] Problem-focused coping strategies were more common in caregivers of bipolar patients and emotion-focused strategies in caregivers of schizophrenic patients. These differences appeared to be linked to differences in caregiver-burden and appraisal between the two groups. [5],[10]

In this survey conducted at a Psychiatric Centre, even when the caregivers were experiencing grieve stress and burden, no caregiver relied or took help from a psychiatrist or a therapist. The caregivers did not consult anyone for their issues.

Conclusion

In summary, this survey suggests that there is considerable literature about the consequences the caregivers of persons/patients with schizophrenia, bipolar disorder and substance use disorder are confronted with, the distress they experience and the coping styles they use to deal with the consequences. Available data suggest that caregiver burden is high in all three disorders. Informal caregivers are the central to the wellbeing of patients. This overview highlighted the need to better understand caregivers' views and personal perceptions of the stresses and demands arising from caring for someone with these illnesses in order to develop practical appropriate interventions and to improve the training of caregivers

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