Original Research Article

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Assessment of caretaker burden in patients with psychiatric illness

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ABSTRACT

Background: There are approximately 450 million people across the world dealing with a mental illness. The burden perceived by caregivers of patients with psychiatric illness is a fundamental prognostic aspect in the history of the disease and the caregiver burden is reportedly a critical determinant for negative caregiving outcomes.

Methods: A cross sectional study was conducted involving 100 caregivers of the patients attending a rural community based psychiatric centre.

Results: A total of 100 subjects (caregivers) were recruited for the study. There were a total of 53 females and 47 males with the mean age of 38.9 years, among them 67% were financially able to take care of the patient. The mean burden score of 69.94 was the major finding in our study. 85% of the subjects accept being frustrated about the slow improvement of the patient. The mean burden score was found to be 69.94.

Conclusions: From present study it was concluded that high amount of burden was present in the study population mostly in their physical, mental and financial condition.

Keywords: Burden, Care givers, Psychiatric

INTRODUCTION

Many people with mental illness must rely on family and friends for support and to help them in their daily activities. Globally, caregivers play an important and ever-expanding role as developments in medical care find new ways to help control illness while health and social services systems are resource- challenged. Caregiver is an individual who has the responsibility of meeting the physical and psychological needs of the dependent patient. Psychiatric patients needs assistance supervision by their caregivers, thereby placing the caregiver at a great risk of mental and physical health problems. The term "caregiver burden" is used to describe "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".¹ As the disease progress, it carries with it a tremendous increase of burden on the caregiver who does the caregiving. The burden perceived by caregivers of patients with psychiatric illness is a fundamental prognostic aspect as the caregiver burden is reportedly a critical determinant for negative caregiving outcomes.

The burden upon caregivers for a mentally ill patient living at home was first acknowledged by Grad and Sainbury in the early 1960's.² The most common mental health consequences identified are depression, anxiety and burnout which occurs when a caregiver slips beyond exhaustion or depression. Studies conducted showed the caregivers reported burden in different areas including effects on family functioning, social isolation, financial problems and health. Most of the notable community-based studies proved that 18-47% of caregivers land in depression.³ It is also known that caring for someone with

psychiatric illness is associated with a higher level of stress than caring for someone with functional impairment from other chronic medical illnesses. Many authors opine that the level of burden does not correlate with the duration of illness, but has enough variability with age, gender and educational status. A previous study concluded that poor social support and severity of illness have major role in determining the amount of burden on a caregiver.⁴

Caring for those with neurological disorders requires tireless effort, energy and empathy and indisputably, greatly impacts the daily lives of caregivers. There are physical, social, emotional and financial impacts of caregiving. As well, though, caring for loved ones with neurological disorders can be rewarding and has many positive, life-giving rewards. Different questionnaires and scales have been developed to quantify the caregiver burden. Caregiver burden is categorized in terms of objective burden (OB), subjective burden (SB) and demand burden (DB). OB is defined as "the extent of disruptions or charges in various aspects of the caregiver's life and household. It measures the disruption of the caregiver's life". SB is defined as "the caregiver's attitude or emotional reactions to the caregiving experience. It measures emotional impact of caregiving on the caregiver". DB measures "the extent to which the caregiver feels the responsibilities are demanding". The assessment of burden has become a challenging task for most researchers because cultural, ethical, religious and other personal values may influence perceptions of meaning and consequences of burden.

There is a dearth of information on burden among caregivers of patients with mental illness in developing countries, especially in community based settings. It is crucial for mental health professionals to be sensitive to the stress and burden experienced by families, in order to plan and implement a comprehensive treatment programme. This would also facilitate enhancing the quality of life of both the mentally ill, and their families.⁵

Objectives

- To evaluate caregiver burden in patients with psychiatric illness.
- To assess the associated factors with the caregiver burden.

METHODS

This is observational cross sectional study. The study was conducted based on a questionnaire, that was pretested, face and linguistically validated. The study and the procedure were explained to all the participants, who were eligible and willing to participate.

Study period: 2 months

Study type: Cross sectional study

Study population: Caretakers of patients attending a tertiary level rural psychiatric health care centre.

Sample size: 100 caregivers were selected based on the inclusion criteria.

Sampling technique: Non-Probability convenient sampling

Inclusion criteria

- Caregivers of patients willing to participate in the study
- Caregivers of patients being treated at psychiatry OPD of a peripheral health care setting

Study tool

Burden assessment schedule

Data collection: The data was collected by using an interview schedule. Interviewer administered a pretested, validated questionnaire. Analysis data was entered in Microsoft Excel and Analyzed by using SPSS version 16 and results depicted in the form of frequencies, proportions and also analyzed for correlations by using suitable tests of significances.

RESULTS

A total of 100 subjects (caregivers) were recruited for the study. There were a total of 53 females and 47 males with the mean age of 38.9 years, among them 67% were financially able to take care of the patient. 41% of them were worried about the patient's financial situation. 58% of the subjects felt that their financial situation has worsened because of the patient's illness to some extent. The efficiency of work of 75% of the subjects was affected by the patient's illness to some extent. 36% of the subjects revealed that the patient causes disturbances at home to a large extent. 56% of the subjects had revealed that their health had not been affected because of patient's illness. 62% of the subjects feel depressed and anxious because of the patient. 46% of the subject's sleep has been affected to a very large extent since the patient was ill. 85% of the subjects accept being frustrated about the slow improvement of the patient. The mean burden score was found to be 69.94.

DISCUSSION

The burden upon caregivers for a mentally ill patient living at home was first acknowledged by Grad and Sainbury in the early 1960s.² Our study revealed a significant burden on the part of the caregiver of a patient suffering from psychiatric illness. A study conducted in Andra Pradesh in 2012 had suggested that the burden on a caregiver is more in case of a patient with psychiatric illness other than chronic medical illness.⁷ In a few studies female caregivers have experienced more stress

and burden than their male counterparts.⁸⁻¹⁰ But our study did not reveal any such differences. This may be due to the limited sample size of our study and the higher prevalence of nuclear families in the western world. A previous study concluded that poor social support and severity of illness have major role in determining the amount of burden on a caregiver.⁴ Our study also depicts high burden with poor social support. This high emotional, financial and physical burden on the caregiver is often neglected. It helps, if the caregiver is also an integral part of the treatment of the psychiatric illness.

Limitations

- Convenient sampling leads to questionable generalizability, and hindrance in the application of the tests of significance.
- Institution based study leads to Berksonian bias.
- Small sample size might have reduced the power of the study.

CONCLUSION

From present study we came across that high amount of care giver burden was present, mostly in their physical, mental and financial condition.

Recommendations

- Multicentric community based studies with larger sample size need to be carried out.
- Improved screening, early diagnosis and treatment facilities towards psychiatric diseases should be of prime importance before estimation of the caregiver burden, specially in rural areas.
- Empowerment of care takers and patients to reduce the dependency and caretaker burden.

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Institutional Ethics Committee

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