Burden of care in the caregivers of patients with mental illness

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Abstract
Families are the most common and most important form of lifelong commitment that an individual does. Mental illness affects the relation of entire family system, to which the family members respond separately leading to different level of emotional, physical and financial burden on the family member referred to as burden of care.

Aim: The aim of the current study is to document the extend of perceived burden of care on the caregiver of a mentally ill person.

Materials and Method: The study sample consisted of 50 caregivers of inpatients and outpatients of psychiatric unit of general hospital attached to medical college, diagnosed as per the guidelines given in ICD-C10. This was a cross-sectional type of analytical, hospital-based study. Caregivers were subjected to the BAS questionnaire which was applied as a self-administered questionnaire in English to those who could understand it, and to the rest of the participants it was administered by interview technique in which the interviewer translated the questionnaire into the vernacular language in which both the patient and the interviewer were well versed.

Results and Conclusion: The study highlighted the need for addressing the burden of care among the different sociodemographic groups of caregivers of the patients with mental illness.

Keywords: Caregivers, patients, mental illness, family system

1. Introduction
The family in its most common form is a lifelong commitment between the man and woman to feed, shelter, and nurture their children till they reach maturity. No two families are the same; they vary as much as their individual members. Nevertheless, the families do share some common features. In particular, they all change over time, and certain processes operate in all of them especially in health and disease. They are usually the primary and social resources for patients. Patients not only depend largely on family support but on the close relatives for their emotional and financial needs as well. Patients suffering from chronic mental illness must be seen in relation to family, relatives and community at large.

The term "caregiver burden" refers to a people's emotional response to changes and demands that occur as they give help and support to a patient or an older person. The burden of care giving has been the subject of rather intense study, a trend, nevertheless will continue with the rapid graying of populations worldwide.

Caregiver is an individual who has the responsibility of meeting the physical and psychological needs of the dependent patient. The term "caregiver burden" is used to describe the physical, emotional and financial toll of providing care. As the disease progresses, it carries with it a tremendous increase of burden on the caregiver who does the caregiving. The caregiver burden in families of psychiatric patients is higher than that of caregivers of other medical illness.

In addition to the emotional, psychological, physical and economic impact, the concept of burden of care involves subtle and distressing notions such as shame, embarrassment, feelings of guilt and self-blame. ‘Burden of care’ has two distinct components (objective and subjective). Objective burden of care is meant to indicate its effects on the household such as taking care of daily tasks, whereas subjective burden indicates the extent to which the caregivers perceive the burden of care [20].
It is, therefore, observed that the perceived burden has a serious impact on the caregiver's physical and emotional health; social relationships and perception; and expression of negative emotions such as frustration, despair, loneliness and anger, which have an influence on the course of the schizophrenic illness of the patient under care.

2. Materials and Method

2.1 Sample

The study sample consisted of 50 caregivers of inpatients and outpatients patients of psychiatric unit of general hospital attached to medical college, diagnosed as per the guidelines given in ICD-10. Sociodemographic details of the subjects were recorded and specially designed questionnaire interview was performed. Each subject included was explained about the study and informed consent was taken. This was a cross-sectional type of analytical, hospital-based study, and caregivers were subjected to the BAS questionnaire which was applied as a self-administered questionnaire in English to those who could understand it, and to the rest of the participants it was administered by interview technique in which the interviewer translated the questionnaire into the vernacular language in which both the patient and the interviewer were well versed.

2.2 Inclusion Criteria

1) Age above 18 years.
2) Caregivers should be first degree relative, and staying with the patient.

2.3 Exclusion Criteria

1) Caregiver of the patient diagnosed as a case of psychiatric illness.
2) Caregiver with obvious subnormal intelligence.
3) Caregiver not blood related to patient, irrespective of the blood relation spouses were included in the study.

2.4 Tools

Burden Assessment Schedule (BAS) by Thara et al. The burden interview has been specially designed to reflect the stresses experienced by care givers of chronic mental illness patients. It can be completed by care givers themselves or as a part of an interview. Caregivers are asked to respond to series of 40 questions about the impact of patient’s disabilities in their life.

3. Results

Distribution among 50 study subjects (care giver) according to the severity of BAS showed majority of subjects 34(68%) had moderate (60-80) burden, followed by 10(20%) subjects had severe (80-100) burden and the remaining 6(12%) had mild (40-60) burden. None of the subjects had very severe burden.

The subjects below 30 years of age seemed to have the maximum burden as compared to the other age group (77.36). Males showed the mean burden of care of 70.98 and females had 72.31. Semi-skilled workers showed the highest burden of care of 77.32 though on comparing with others statistical significance was not established. Care givers of patients with Alcohol dependence syndrome reported the highest burden of care (90.92)

Highest score of BAS were associated with the highest duration of care giving, 10-20yrs of duration of caregiving showed mean BAS score of 77.31. The group with the contact hours of 2-8 hours had a mean BAS score of 71.07 and the group with the contact hours of more than 8 hours had mean BAS score of 72.99.

The caregivers of the patients with the duration of illness of less than 7 years should a mean BAS score of 78.52 and the caregivers of the patients with the duration of illness of more than 7 years had a mean BAS score of 86.16. Caregivers as a spouse had a mean BAS score of 73.26, those as children had a mean BAS score of 76.08, those as parents had a mean BAS score of 70.08. Families of lower or upper lower class had the highest mean BAS score of 75.21.
4. Discussion
The mean age of the care giver group was 43.5 years; the range was 22-66 years. 50% of the subjects (caregivers) were male. The majority (88%) were Hindus. 78% subjects were literate. All of the caregivers were employed.
Scores on BAS of the Care givers of patients with Alcohol dependence syndrome reported the highest burden of care. To test whether this difference is statistically significant ANOVA test was applied. The F-value was 5.93 which is statistically significant (\( P < 0.001 \)).
The subjects with duration of illness more than the mean (7.01 years) reported higher burden of care on BAS than the subjects with duration of illness less than the mean. To test whether this difference was statistically significant Mann-Whitney test was applied. The Z-value was 2.28 which is statistically significant (\( P < 0.05 \)).
BAS scores seemed to increase with the duration of caregiving but without any statistical significance.
A positive correlation of burden of care with the duration of illness was found. Burden of care increases with the increase in duration of illness of the patient. Z-test was used to find the association.
Children as the caregiver showed the highest burden of care. To test whether this difference is statistically significant ANOVA test was applied. The F-value was 3.72 which is statistically significant (\( P < 0.05 \)).

5. Reference