

Caregivers' burden of the patients with mental illness: An update

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Summary

A person who provides direct care to the person with any illness called caregiver. Caregiver burden refers to the emotional, social, and financial stresses that caring for a relative or friend with mental illness imposes on the caregiver. Literature search was done by library work and med line search with the key words 'burden' 'caregivers' 'mental illnesses' and 'mental disorders'. The quality and pattern of burden of caregivers of people with mental illnesses may experience a different than is seen with other illnesses. The emergence of community-based method of psychiatric treatment and the decrease in economic resources have led to a shift in the responsibility for the care of the mentally ill individual from the institution to the community. Now the trend is hospitals reduce their own burden, which passes on the family. Many mental illnesses like schizophrenia, mood disorders need chronic care and their family and friends provide their nursing. The caregivers feel subjective burden and sometime they also suffer from psychiatric illness. In Bangladesh the hospital for mental illnesses are limited in number and the number of mental health professionals are not adequate against the need. Moreover the issue of psychiatric nursing is not well addressed. For that reason the family members are responsible for caring. In this context service providers need to better understand caregivers' views and personal perceptions of the stresses and demands arising from caring for someone with mental disorders. This will be necessary in order to develop practical, appropriate, and acceptable interventions, and to improve the training of professionals working with caregivers.

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Introduction

The term caregiver burden refers to the emotional, social, and financial stresses that caring for a relative or friend with mental illness imposes on the caregiver¹. Caregivers of people with mental illnesses may experience a different quality of burden than is seen with other illnesses. A better understanding of their concerns is necessary to improve the training of professionals working with this population. Conceptualizing caregiver burden in a conventional medical framework may not focus enough on issues important to caregivers, or on cultural and social issues. Perceptions of caregivers about mental illnesses have important effects on levels of burden experienced. It is important to distinguish between caregivers' experience of this subjective burden and objective burden as externally appraised. Subjective burden is defined as the emotional response of the caregiver to the behavioral and social difficulties of the ill person and to the consequences of the ill person on the household². The emergence of community-based method of psychiatric treatment and the decrease in economic resources have led to a shift in the responsibility for the care of the mentally ill individual from the institution to the community. Now the hospitals were relieved of burden, which was passed on the family. The families and the community at large were ill prepared to receive the patients discharged from asylum. Objective caregiver burden is comprised of those tasks required to care for the client, whereas subjective caregiver burden indicates the extent to which the caregiver "minds" performing these tasks³. In majority cases family members are now seen as a principal source of support and an important partner in the rehabilitation of the mentally ill in developing cultures with recent estimates indicating that between 1/3 and 2/3 of persons with mental illness currently reside with family members⁴. Mental

illnesses are major cause of suffering for patients, but the burden it indirectly imposes upon families and caregivers is a matter of increasing clinical concern. Caregiver burden has been described as 'the presence of problems, difficulties or adverse events which affect the lives of the psychiatric patient's significant others, e.g. members of the household and/or the family' although significant others can be considered to extend to include close and supportive friends⁵. It is known that people who care informally for those with long-term illnesses suffer from increased levels of stress, depression and ill-health^{6,7,8}. Service providers need to better understand caregivers' views and personal perceptions of the stresses and demands arising from caring for someone with mental disorders. This will be necessary in order to develop practical, appropriate, and acceptable interventions, and to improve the training of professionals working with caregivers. It is likely that there are complex inter-relationships between the breakdown of informal caring relationships, increasing social instability, the need for input from formal/professional caregivers (including psycho education), and health and economic outcomes of care. If caregivers' beliefs about mental illnesses are primarily based on cultural as opposed to medical models of illness, mental health professionals need to make aware of this when offering psycho education and support to individuals and groups of caregivers. In Bangladesh the numbers of health care professionals are not adequate against the need and moreover mental health professionals are also very limited in number. For that reason the caregivers of the patients are integrated part of mental health care delivery system. These caregivers also possess burden due to their ward with mental illness.

Literature search strategy

Possible literature search was done by library work, and med line search with the key

words 'burden' 'caregivers' 'mental illnesses' and 'mental disorders'. Library of Bangabandhu Sheikh Mujib Medical University, National Institute of Mental Health library and National library were searched also for the relevant publications regarding this issue. Researchers also searched through HINARI (Health Inter Network Access to Research Initiative) and PUB Med Search engine for online literature.

Discussion

Studies in the western culture have shown a moderate level of caregivers' psychopathology and burden with correlates being clinical characteristic like patients' symptoms and socio-demographic variables and caregivers' socio-demographic factors and coping abilities⁹. Some studies from sub saharan Africa had suggested high level of burden associated with socio-demographic variables of the caregiver and higher symptoms level in the patient^{10,11,12}.

A research findings usefully differentiate between interventions that aim to have an impact directly on caregivers from those that use the caregiver as an 'agent of change' for the person with dementia and those that combine these approaches¹³. For example, interventions may target caregiver self-care (e.g. social support, stress management), caregiver appraisal of the person they care for (e.g. providing information about the illness, or modifying attributions and beliefs about the illness and locus of control, etc.), or promote caregiver skills (e.g. cognitive stimulation, pleasurable activities, behavior modification). This conceptualization could be usefully transferred to the field of bipolar disorders, allowing us to develop psychosocial interventions with informal caregivers. However, before this is possible, it would be helpful to develop a thorough and in-depth understanding of the nature of caregiver burden in relation to bipolar disorders. When conceptualizing caregiver burden we need to recognize that caring roles

are usually an integral part of family life. Parents generally expect to have to care for their children, children are dependent upon their parents or guardians, and many spouses care for their partners. Thus, a level of caregiver burden usually exists within family roles and relationships, and the implicit or explicit obligations these carry with them. These are, in turn, shaped by cultural and social class expectations. For example, in a relationship characterized by traditional gender roles, the care burden experienced is likely to differ substantially depending on whether the husband or the wife is the patient. Burden is also related to the development and nature of a person's self-identity in their role as caregiver. Most people who view themselves as informal caregivers have experienced an important transition in which the relationship of 'carer-cared for' has become superimposed onto existing spousal, family, or friendship relationships. These qualitative changes in the relationship between informal caregiver and patient are likely to be associated with specific symptoms, key illness-related events, and the stage of the disorder, yet very little is known about the factors mediating these changes with respect to bipolar disorder. A study on caregiver's burden describes three ways in which people take on the identity of informal caregivers: (i) in the context of positive long-term relationships, (ii) as a result of feelings of duty and obligation, and (iii) in relation to strong feelings of anger and resentment¹⁴. Each of these situations probably needs to be approached in a different way rather than via a generic approach, but can only be done if the patterns and their various combinations are recognized.

Caregiving may have an economic impact in various ways. Informal caregivers may take time off from paid work to fulfill caring obligations, choosing not to work full-time, being unable to offer the flexibility that employers might normally require and thus

not fulfilling their potential in economic/career terms, etc. There are also direct economic consequences and there is evidence that family members, especially parents and siblings, often make significant financial contribution to the support of their relatives with mental illness¹⁵.

The UK government has recently recognized that the large number of informal caregivers have needs in their own right. Caring about Carers: a National Strategy for Carers attempts to address three issues: information, support and care for caregivers¹⁶. There is recognition of a relative paucity of reliable information about caring activities, and promotion of a two-way information exchange between caregiver and service providers to redress this. The need to support both informal caregivers' care activities and their psychological needs is acknowledged through; for example, regular breaks from care giving activities. If such well-meaning government interest is to be successfully translated into effective action, more research will be needed to reliably chart the nature of informal care giving experiences. It should be recognized that these caring experiences are likely to vary depending not only on the disorder of the person being cared for, but also on caregivers' and patients' relationships and social circumstances.

In the literature on schizophrenia, dementia, and unipolar depression, the burden upon informal caregivers is common, if not universal, and has significant impact on multiple domains of life¹⁷. The perceptions and beliefs of caregivers about the specific disease have important effects on levels of burden experienced¹⁸. It is important to distinguish between caregivers' experience of this subjective burden and objective burden as externally appraised, as the two may be surprisingly discrepant. Caregivers' previous experiences (negative or positive) of mental health services may strongly influence the beliefs and expectations they have about the illness¹⁶. Caregiver burden is strongly

associated with caregiver depression, which affects patient recovery by adding stress to the living environment and the caregiver not being able to provide enough support for the patient. In schizophrenia, informed interventions on the part of the family can reduce the burden of disease¹⁹.

One study was based in a US Veterans Affairs centre, which assessed the primary caregiver to 266 bipolar patients on illness appraisal (awareness of mental illness, and the volitional nature or otherwise of symptoms or behavior), social adjustment, and burden (objectively, subjectively and globally rated), and only spouse/equivalent caregivers were included; sibling and non-spouse caregivers were excluded¹⁸. Severe levels of burden were reported by over 50%, and moderate or severe levels were reported by over 90% of the caregivers interviewed. This study has limitations, including 10% of patients having bipolar II in the sample and a large proportion of patents with schizoaffective disorder (35%). Further limitations may arise from the possible lack of sensitivity or selectivity of the rating instrument used to detect the unique features of bipolar caregiver burden, the rationale for the assessment period (within 2 weeks of discharge), and the fact that no data were presented in the initial study about the polarity or duration of the index mood episode¹⁸.

These factors may account for findings that one found the highest burden was related particularly to misery, irritability and withdrawal, i.e. depressive episodes were rated as significantly more burdensome than manic/hypomanic episodes¹⁸. Although they accepted that the duration of depression is long in bipolar disorder we cannot believe severe manias have no significant impact on care burden and patient-caregiver relationships. Nevertheless, at follow up high caregiver burden at the index rating predicted ongoing affective episodes at 7 and 15 months²⁰. One interpretation of this

finding is that patients living with an 'overburdened' caregiver may have an increased risk of relapse.

An Indian study revealed that the objective burden on caregivers of hospitalized patients and outpatients with bipolar disorder was significantly higher than for those with unipolar depression²¹. A number of smaller studies appear to support this finding in other settings, examining burden of care in siblings of individuals with severe mental illness, the perceptions of relatives and professionals of family burden in schizophrenia, and a comparison of caregiver burden in Black, Hispanic and White families^{22,23}.

The concept of family resilience offsets the focus on burden and tries to explain why some families experience lower burden and greater reward. Family resilience includes the ability to develop adaptive interpersonal skills, such as differentiating the person from the illness and family qualities such as mutual acceptance and empathic involvement²⁴. These strengths may contribute to an overall sense of a family well-being and offset difficulties in other areas of family functioning. For example, a warm and supportive attitude towards the care recipient can offset difficulty with the role of caregiver. Many caregivers spontaneously report satisfaction and a sense of reward from care giving, thus it is important to use a family research tool that measures a family's strengths and weaknesses in many different areas. One model of assessment, the McMaster Model of Family Functioning assesses a broad range of family functions including affective involvement, affective responsiveness, roles, communication, behavior control, problem solving and an overall measure of family functioning²⁵. The associated self-report questionnaire, the Family Assessment Device, has been extensively used in family research²⁶. Caregivers who are critical, hostile, or emotionally over involved with their relative report higher burden²⁷.

Caregivers report fewer burdens when they understand that their relative's behavior is caused by illness and not by the patient's personality. Caregiver intervention studies have been shown to improve caregiver quality of life^{28,29}. Few caregivers seek out support for themselves, however, even though this may result in reduced burden and a stronger sense of family competence^{30,31}. Caregiver treatment refusal rates are 25-50% and may reflect a denial of illness, lack of understanding of the rationale for intervention or a perception of "no acute need"¹⁹.

In Bangladesh a study was done on chronic schizophrenic patients to assess the psychopathology and functioning, family difficulties which were ascribed by the patient, family's financial and also household functioning³². Other parameters related to patients like social isolation, alcohol and drug abuse, antisocial behaviors, occupational role functioning and psychopathology of children were also looked into. This study was done by two stages interview of the family. Results revealed that patients with schizophrenic illness had the most severe and disruptive psychopathology. The families with schizophrenic patients were most distressed and socially isolated³². They had difficulties in the areas of household functioning, financial and community problems. The distress felt by the family and the burden and problems due to patient's illness were significantly correlated with the severity of the patient's psychopathology.

After reviewed the above mentioned literatures reviewers can infer that burdens experienced by caregivers of people with mental illnesses are associated with problems in health, mental health, interpersonal relation, and cost. These studies have shown adverse consequences of high levels of burden for both caregivers and patients. Because the caregiver's ability to effectively manage the challenges of caring for a family

member with mental illness is a critical component to the health and well-being of both patients and caregivers, For better management of the patient with mental illnesses, clinician should evaluate the impact of caregiver burden and coping on adverse health and mental health outcomes of care giving over time.

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