# Care Givers' Experiences in Families Living with Mentally Ill Patients

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**Abstract:** *Family members play vital role in care of persons with sick especially with mental illness living in families. Their care is multiple in terms of taking day-to-day care, supervising medications, taking the patient to the hospital and looking after the financial needs as well as to bear with the behavioral disturbances of the patient. Thus, the family caregiver experiences considerable stress and burden, and needs help in coping with it.*

*The present study assessed the experiences faced by care givers in care of mentally ill patients living in their families. It is a part of UGC sponsored minor research project. The four rural areas were selected to assess around 100 participants who were taking care of mentally ill persons in their families. The Convenient sampling technique was adopted for selection of samples by making house-to-house visits, interviewing, and assessment of care giving and living conditions in the families. A Semi-Structured questionnaire was used for this study. In the process of development of the tool the investigator reviewed the secondary data on Mental Illness and the validity of the questionnaire was discussed with subject experts from the field of education and health profession and developed the tool.*

*Major findings were assessed based on the results of the study. According to this research there is mental illness existing in families, most of family members feel that mental illness is a burden, there is negative opinion (stigma) among family members. An unhealthy coping style is likely to adversely affect the care giving function. Hence, it is important to take care of the needs of the family caregivers. The family caregiver has remained as a neglected lot, often ignored by the mental health professionals. This key support system can't be taken as granted and ignored. Further studies required to provide accurate information for assessment and effective care giving strategies to cope their burden and issues in care giving*

**Key Words:** ***Care Giving, Mental Illness, Patients and Family etc.***

## Introduction

Family caregivers play a critical role in supporting, infirm and long term care system by providing a significant proportion of the care for ill persons living in the families. With regard to mental health problems in families, especially when a person is living with a serious mental illness, the whole family may be affected. This situation may bring significant levels of stress for the caregiver and can affect their overall quality of life including work, socializing and relationships. Research into the impact of care giving shows that one third to one half of care givers suffer significant psychological distress and experience higher rates of mental ill heath than the general population. Care giver plays multiple roles in care of persons with mental illness, including taking day-to-day care, supervising medications, taking the patient to the hospital and looking after the financial needs. The family caregiver also has to bear with the behavioral disturbances in the patient. Therefore care giving to patients is psycho-social based.

## In Indian context

Mental illness is a global public health concern. According World Health Organization estimation, mental disorders constitute 14% of the global burden of disease and the overall prevalence rate of mental disorders in India is 10-12 percent. In addition, the Global Burden of Disease Study 2010 (GBD 2010) stated that major depressive disorder is one of the top five leading causes of Years Lived with Disability (YLD) in India. Being a developing country, in India there are paucity of mental health professionals for instance, psychiatrists <0.5 per 100,000 population. Majority of the population live in rural areas and it was found that about 80% to 90% of the mental disorders were undiagnosed and untreated due to lack of knowledge and negative attitudes toward mental illness. Further, stigma and negative attitudes toward people with mental illness have been observed to be common worldwide among general population

In Indian culture, family is regarded as the most important structure in caring for vulnerable family members including those with mental illness and more than 90% of patients with chronic mental illness live with their families. Families of Indian patients with mental illnesses have always been involved in their care. Such involvement arises both from choice as well as the compulsion of being a part of an inadequately resourced mental health system.

The caregivers not only provide the basic needs of care like long-term assistance of housing and financial aid they also take care of the day-to-day needs of the people with mental illness, monitoring the mental state, identify the early signs of illness, and relapse and deterioration, and help the patient in accessing services. The family caregiver also supervises treatment and provides emotional support to the patient. However, the lack of knowledge and relatively lower mental health literacy pose challenges to family caregivers, mental health patients and service providers. An extensive body of Indian research on caregiver burden in a number of mental illnesses shows that providing care for a relative with mental illness is associated with considerable distress and burden for the family caregiver Subho Chakrabarti, (2016). Nevertheless, the Indian evidence for the efficacy of formal family-based interventions remains inadequate and lacks methodological precision. Finally, day-to-day practice in clinical settings does not seem to have made use of the ample body of research evidence in this area to help families in distress. Interventions are likely to prove to be a greater challenge than for developed nations, because of the scarce resources and a multiplicity of other social, economic, and cultural hurdles in India. It goes without saying that much more research is required in this area before mental health professionals in this country are able to find effective ways to help families cope with the adverse consequences of providing care.

## Care Giving Burden

Care giving associated with emotional and cognitive transformations. This experience leads to the physical, psychological and social impact. India, as well as in most of the nonwestern world, and to a lesser extent in other parts of the world, families have been the mainstay of care giving for persons with mental illnesses. Burden of care" is defined as "the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patients' significant others (e.g. members of the household and/or the family)". The concept of 'burden of care' has two distinct components - the objective and the subjective. Objective burden encompasses measurable effects in household disruptions, economic burden, caregivers' loss of work, social, and leisure roles, and time spent negotiating the mental health, medical, social welfare, and sometimes criminal justice systems. In contrast, subjective burden is the caregiver's own perception of the impact of caring. It consists of the negative psychological impact on the caregiver and includes feelings of loss, depression, anxiety, anger, sorrow, hatred, uncertainty, guilt, shame or embarrassment, all of which result in much distress and suffering.

Family care giving for mental illness needs to be distinguished from the usual caring, which is age and culturally appropriate. Studies have shown the highest negative impact, where a substantial majority (30%-60%) of caregivers suffer significant distress, Barrowclough C (2005). Because of multiple role that care givers need to play in taking care of ill patients, their treatment and other house hold activities may affect adversely and continuous stress may impact on their physical and mental health as well as on their emotional wellbeing.

## Knowledge and Attitude on Mental Health/Illness

Families are a primary care giving resource for persons with mental illness, yet they often lack the knowledge and skills needed to assist their relatives. Studies show that families routinely request information on basic facts about mental illness and its treatment, behavior management skills, and the mental health system in order to better cope with their relatives' illness. Shinde, M., and Anjum, S., (2014).

The individuals with mental health problems were experiencing severe and enduring mental health problems as defined by the Scottish Framework for Mental Health Services, Scottish Executive, (1997). Mental illness, despite centuries of learning and the Decade of the Brain', is still perceived as an indulgence, a sign of weakness. Stigma, prejudice, and discrimination are closely related and tightly interwoven social constructs. Stigma, prejudice, and discrimination against those with mental illness cut across all classes and social groups.

Caring for a relative with a mental health problem is not a static process since the needs of the care recipient alter as their condition changes. Being a care giver can raise difficulties in personal issues about duty, responsibility, adequacy and guilt. It's not anomalous to feel ashamed, or hurt, or mortified by a family member whose behaviors can be difficult to understand and deal with. In other ways families commonly report 'stigma by association' resulting in discriminatory and detrimental behaviors towards patients. In some communities stigma coupled with mental illness brings shame to a family and can affect the marriage potential of their relatives, so families keep the illness private and are often unwilling to seek professional help. In some communities religious and spiritual beliefs are linked to mental illness and in some cases, influence the treatment. Thus, the family caregiver experiences considerable stress and burden, and needs help in coping with it. The present study focuses on the burden experienced by the family caregivers, assessing knowledge and attitude of patients' relatives towards mental illness seems meaningful so that various mental health professional help and intervention programmes could be formulated and organized. This will also help in proper rehabilitation of the patient. Acquiring knowledge and having positive attitude may help family members to understand and provide better care for the ill persons living in their families.

## Methods and Tools

The present study assessed the perceived knowledge and attitude of care givers and experiences burden of care faced by them in case of mentally ill patients living in their families. The study was carried out among selected four rural areas of Dakshina Kannada District. Convenient sampling technique was used to select 100 care givers and **Collected** data by making house-to-house visits through interview and among those who were willing to participate in the study. The study criteria included: (i) He/she must be relative of patient (family member) and diagnosed as mentally ill as per ICD-10. (ii) Care giver (respondent) should be above 18 years. (iii) Must be the main caregiver, (iv) caregiver must have taken care of the mentally ill for more than 6 months. A semi-structured questionnaire was used to assess and in the process of development of the tool, the investigator reviewed the secondary data on Mental Illness and the validity of the questionnaire was discussed with subject experts from the field of education and health profession discussed with experts and developed the tool.

The first part of the questionnaire included socio-demographic details of participants. The second part of the questionnaire collected information regarding mental health literacy of the caregivers by using Family living conditions (burden of care, difficulties and adjustment) which consists of 9 items, attitude toward people with mental health problems (12 items), and knowledge on mental health and illness (15 items). Answers were coded on a 5-point scale for attitude (Strongly Agree, Agree Somewhat Agree, Disagree, and Strongly Disagree) and for knowledge 3-point scale (Good, Poor and Average). Investigator visited Taluk Panchayat and local health care centers to seek permission as well as to collect statistical information. Study was assessed by appointed trained field workers. Descriptive statistics were used and results were narrated in the form of tables and graph.

## Results

Study shows the socio-demographic attributes of the sample. In keeping with the demographic and economic profile of participants, the sample was predominantly young and most came from low or low average income households. The present study investigated mental health literacy among 100 caregivers of the persons with mental illness, of whom majority of the participants (53%) were aged between 21 and 40 years. The majority of the participants were married (76%) and Hindus (49%). Nearly half (42%) of the participants were illiterates/primary education Almost all participants (95%) of the caregivers were family members. Merely 89% families availed from middle class, poor having low average income.

**Table 1: Family Living Conditions in Terms of Demographic Characteristic**

| **Demographic** | | **Burden of Care 100%** | **Difficulties 100%** | **Adjustments 100%** | **Total 100% (Affected)** |
|---|---|---|---|---|---|
| Age | 21-30 | 20 | 12 | 07 | 13 |
| | 31-40 | 16 | 14 | 07 | 12.33 |
| | 41-50 | 11 | 12 | 09 | 10.66 |
| | 51-60 | 06 | 03 | 04 | 4.33 |
| Sex | Male | 28 | 18 | 12 | 19.33 |
| Female | 25 | 23 | 15 | 21 | |
| Education | Illiterates | 19 | 14 | 08 | 13.66 |
| | Primary | 11 | 09 | 06 | 8.66 |
| | Secondary | 08 | 06 | 04 | 6 |
| | Till S.S.L.C (10th) | 06 | 04 | 02 | 4 |
| | P.U.C | 04 | 02 | 03 | 3 |
| | Degree (UG) | 02 | 01 | 01 | 1.33 |
| | Higher studies (PG & others) | 00 | 00 | 00 | 00 |
| | Technical (IT & others) | 03 | 05 | 03 | 3.66 |
| Family | High | 03 | 02 | 04 | 3 |
| Income | Average | 23 | 17 | 10 | 16.66 |
| | Low | 27 | 22 | 13 | 20.66 |
| | **Total** | **53%** | **41%** | **27%** | **40.33%** |

It is obliviously difficult for families to cope with mentally ill patients. It can be physically and emotionally tiring, and can make them feel vulnerable to the opinions and judgments of others. Caregivers who attempt to balance care giving with their other activities, such as work, family, and leisure, may find it difficult to focus on the positive aspects of care giving and often experience more negative reactions, such as an increased sense of burden (Pavalko E, Woodbury W, 2000). The present study portrays the care giving experiences (affect) of care providers. The affect of mentally ill patients living in families divided into three components which consisted of 9 (3 each) items and asked care givers if the questions were Yes or No. The results were described as burden of care in terms of finance, stress, care giving, difficulties in terms of understanding illness, communication, awareness and adjustment in terms of relationship, job, household activities. Detailed results were shown in table no.1 in relation to demographic profile of the care giver. It also describes how socio-economic conditions affected the care giving of mentally ill patients in families.

As per study concerns, overall a little more than half of the care givers 53% felt burden in terms of stress, 41% of them had difficulties in understanding, awareness on mental illness, communicating with them and 27% of them faced adjustmental problems in living with mental patients in their families. Care giving responsibilities can have a negative effect on work roles as caregivers adapt employment obligations to manage and meet care demands as well as to have good relationship with other family members.

Results of the study on family living conditions by family members are categorized in the form of demographic characteristics. Majority of the caregivers were below the age of 21 to 40 years. The responsibility of care giving seems to be more with the younger members in the family constituting wives, siblings, their children and their spouses. Among them affect of mental illness was 25.33% (21-30, 13% and 31-40, 12.33%). Majority of the care givers affected were females 21%, illiterate people 13.66% were more affected than others and family living condition is usually affected mostly due to poor economic condition 20.66% which was proved in this study. Overall 40.33% of family members felt that their family living condition was affected due to mentally ill patients living in their families.

This study revealed psychosocial, emotional, economic, and physical challenges caregivers undergo in caring for their relatives saddled with mental illness.

The findings point out to problems such as: stress, lack of support or social service provision, poverty due to their inability to work full time resulting in financial difficulties, and general societal stigma of living with someone with mental illness. It is very true that mentally ill person's condition is not in normal condition, which affects daily living and also it affects the family atmosphere. Many times family fails to function. There will be family burden and other related issues taking place.

**Table 2: Mental Health Knowledge among Family Members of Mentally Ill Persons**

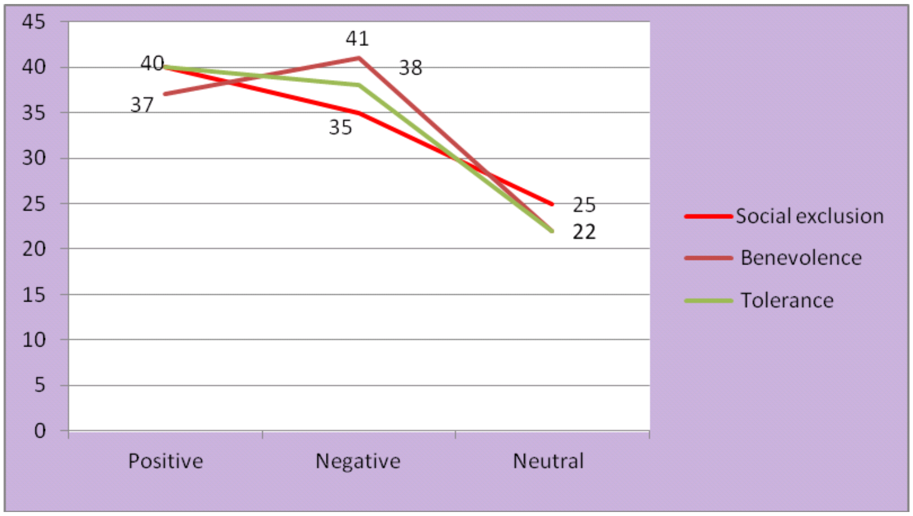
| Mental Health Knowledge | Good | Poor | Average |
|---|---|---|---|
| **Help-seeking** | 41 | 37 | 22 |
| **Recognition** | 41 | 43 | 16 |
| **Support** | 38 | 41 | 21 |
| **Employment** | 43 | 41 | 16 |
| **Treatment** | 60 | 30 | 10 |

Public stigma against people with mental health problems is damaging to individuals with mental illness and is associated with substantial societal burden. It is a global phenomenon, which is prevalent and persists over time attempted to explore young people's knowledge relating to mental health and mental illness

Study comprised five items covering stigma-related mental health knowledge areas. These statements covered a wide range of issues, including stigma, the likelihood of becoming mentally ill, and the possibility of cure and medical treatment for persons with mental illness. As per table no. 2., describes health seeking aspects in terms of whether they desire to take ill patients to health facilities and opinion towards health professionals where 41% of them had Good, 37% poor and 22% average knowledge. Recognition aspects whether mentally ill patients are needed to be recognized and need to be treated and given well care where 41% good, 43% poor, and 16% average knowledge. In terms of support whether care givers required to support mentally ill patients around 38% good, 41% poor and 21% average knowledge. Employment related aspects were whether mentally ill patient can be employed 43% good, 41% poor and 16% had average knowledge and treatment of mentally ill patients majority of them i.e., 60% had good, 30% poor and 10% average knowledge among care giver.

Despite the apparent knowledge gap that many have about mental illness. It shows that there was an almost equal percentage (between 38% to 43%) of the family members who had mental health knowledge as well as stigma related mental health knowledge. In terms of treatment aspects majority (60%) of them were in favor of it. Care of mentally ill patients and effective treatment is based on the knowledge acquired by people. Therefore need of awareness among family members of the mentally ill persons is still required.

**Figure : Attitude Towards Mental Illness among Family Members**



## Attitude Towards Mental Illness Among Family Members

Mental illness often constitutes a double jeopardy for those affected because of stigmatization by members of the community (Corrigan and Watson, 2002). An episode of mental distress will disrupt the lives of people so that they are pushed out of the society in which they were fully participating. As per shown in the figure. Respondents were also asked to agree or disagree with a series of attitudinal statements about mental illness. The participants who took part in this study held negative views about the mentally ill. Study assessed three components regarding attitude towards mental illness and mentally ill persons, they are, firstly 'Social Exclusion', or 'Social Marginalization', is the social disadvantage and relegation to the fringe of society. 40% of the family members were in favor of Social Exclusion; 25% of them stood neutral and 35% were not in favor of it. They think that person living in families with mental illness may lose reputation of the family therefore keeping away from family relationships is a better solution. Secondly, 'Benevolence' in terms of helping a mentally ill person seek assistance and treatment as soon as possible will help them and their carer/family deal with the issues they are facing, and ultimately improve their quality of life. The majority i.e., 41% of the family members disagreed to it, they feel that mental illness is untreatable, 37% of them are in favor of it. Thirdly, 'Tolerance' it terms of behavior, care taking, acceptance, treatment and condition of the illness. 38% of them feel that being tolerant is impossible.

Negative views such as those implying on people with mental illness are irresponsible and therefore incapable of making their own decisions, or are dangerous and are to be feared, are widespread. Since negative beliefs often lead to discrimination, there is little wonder that studies have also shown that people with mental health problems living in the community experience rampant harassment (Kelly and McKenna, 1997; Berzins *et al*, 2003). Understanding mental illness and condition of mentally ill patient help care providers to look for healthy care giving strategies which enhance the quality care as well as improve the condition of the mentally ill persons.

## Suggestions and Conclusion

Present study has aimed to examine mental health literacy and family conditions among caregivers of people with mental illness. It attempted to investigate the caregivers mental health literacy factors such as etiology, knowledge, attitude, management, components of attitude on social exclusion, benevolence, tolerance and components on family living conditions such as of people with mental health problems. Study shows that taking care of family member with mental illness is stressful and range of socio-economic factors are responsible for burden in care giving. Family members feel that mental illness is a cause for losing reputation of family therefore it is better that person has to be excluded in all family activities or functions. It shows that participants have negative attitudes towards mentally ill. Study demonstrates that Mental Illness has more negative impact on caregivers. Due to continuous illness, caregivers have to spend more time when their family member is symptomatic as they need to care for their personal hygiene, calm down during emotional outburst and take the brunt of abuse and assaults from their mentally ill family members. Caregivers' involvement in direct and indirect care changes over time, in response to the stage of illness and treatment, and caregivers must be able to adapt to changes in the amount, level and intensity of care demands. Caregivers often take the support of other family members during acute phase in order to deal with the stressful situation of caring mentally ill during symptomatic phase. Care giving for chronically mentally ill family members disrupts the normal functions of families, and it almost always causes stress in the family. There are primary stressors, caused by performing the work required to care for the sick family members, and secondary stressors, problems that emerge in social roles and relationships as a result of care giving. These stressors highlight the fact that care giving work is not only stressful because it requires the performance of difficult physical care and medical care like administering medicines, follow-ups, involvement in productive work and encouraging, but also because of secondary stressors: Marital discord, social isolation, economic strains and family dysfunction. These results have considerable implications for the way in which relatives should be dealt with as part of the overall management of persistent burden of care. It also requires effective coping strategies to take part in treatment and giving care of mentally ill patients.

The caregivers' needs should be understood and addressed. There is a need for developing psychosocial interventions for caregivers in order to address their mental health and their needs. Caregivers needs of caring and concerns of caring should be supported in order to enhance the quality of care and to reduce the burden of caring. Family is a principal source of support and an important partner in the rehabilitation of the mentally ill. The responsibilities are most often assumed by the immediate family member, carries the heaviest part of the family burden. The caregivers should be acknowledged and looked as resource in the mental health programme. The caregivers should be included, consulted and their voices should be recorded while we draft the mental health policy for the country. The National Mental Health Progamme should incorporate caregivers as resources and initiate programme for enhancing the well being of unheard caregivers. Family based interventions have proven efficacy in reducing relapse rates and negative impact of psychosis on caregivers and can reduce negative attitudes and increase the willingness in the caregivers in providing care to patients. The psycho-education sessions can be given importance which may include a brief introduction to the illness, presenting symptoms, early signs of relapse, available treatments and their efficacy, safety of treatment, common side-effects, treatment related costs, identifying burden, and coping methods. Day-to-day problems in the management of patients should be discussed, and simple and practical solutions may be offered. Simple behavioral interventions like anxiety and stress management may be undertaken. Sessions can be held weekly or fortnightly initially and later once in a month. Number of group members may vary from 10-12 to 15-16. Structured psycho educational interventions consisting of monthly sessions for 9 months have been found to be significantly better than routine out-patient care on several indices, including psychopathology, disability, caregiver-support, and caregiver-satisfaction. There is a need to spread community awareness about the mental illnesses and a message that most of the mental illnesses can be easily treated and the patient can live a nearly normal life in the community. This would help in bringing down the stigma associated with mental illnesses and help integration of persons with mental illnesses in the society, and in turn reduce the stresses faced by the caregivers. There is also need to establish community-based mental health care facilities, which will reduce the distances travelled by patients with mental illness and their caregivers to seek treatment. Long-stay facilities are required for persons with mental illness, who don’t have any family members to look after or the family members are not in a position to take care of them due to ill health or old age. At present, treatment of mental illnesses is not covered under medical insurance, which is the need of the hour. Awareness programmes need to be organized regarding provision of disability pension due to mental illnesses. The Government has taken some steps in these directions under the National Mental Health Program and in the forthcoming Mental Health Care Bill. But still, a lot is need to be done in this direction.

The present study highlighted that almost half of the participants are holding stigmatizing attitudes towards people with mental illness in relation to social participation, treatment, work, marriage and recovery. Most of them face burden in care giving to mentally ill patients and their knowledge towards mental health still has to be enhanced because only they come to know when they go for treatment. Thus, there is an urgent need to educate and change the attitudes of the caregivers regarding mental illness through mental health literacy programs specifically on certain groups within the population who have a particular need for mental health education. Further, mental health professionals should take responsible role in educating these specific populations. Thus, it is necessary to understand the role of caregiver in the recovery process, adequately acknowledged and recognized, often to be reminded so that they would recognize their roles themselves, would act as motivating for them to continue to care their mentally ill family member. There exists a need for developing specific intervention package to empower the caregivers, need to see them as resource rather than just recipients of mental health services.

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