

Caring for Family Caregivers of Persons with Mental Illness: The Social Work Perspective

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Abstract: *Family caregivers play important role in providing care to the persons with mental illness. The gravity of mental illness on lives of family caregivers is very significant. Family caregivers are not the professionals but they take up the major task of caring for mentally ill persons in their family as the primary caregivers. Most of the times caregiver's health is neglected in the process of care giving to persons with mental illness. Therefore, it becomes important to understand their situations, challenges as well and care for their needs as a holistic approach. But we hardly find any institutions or services addressing their specific issues unless they turn up as patients themselves. The objectives of the study are to understand mental illness and the role of family caregivers. It also tries to understand their challenges and impact of mental illness on their lives. It aims to draw the necessary attention towards their problems so that required measures can be initiated. This article tried to review literatures to reflect the existing data and findings on mental illness, its severity, impact and the important role played by family caregivers. With this article, the researcher tries to emphasize the important role played by family caregivers, throw light on the caregiver's issue which are often overshadowed by the problems of patients. The purpose is to draw required attention and action as a holistic health care approach for both the patients and their caregivers simultaneously. **Method:** This article tried to review literature across places and times to have an overview of mental illness, its challenges. Most importantly it tries to highlight the roles played by the family caregivers and challenges that they face in the care giving process.*

Keywords: Family caregivers, mental illness, caregiving, impact, burden, holistic care

1. Introduction

The problems and sufferings of each person with mental illness is unique along with common generalised characteristics of each illness since each individual is unique and the way they perceive things and respond varies. These people experience heightened emotions, distress, hopelessness, obsessive thoughts, suicidal thoughts and very often get violent. In many cases they are dependent on others even for their daily chores and personal care.

As per the National Mental Health Survey, 2015 - 16 conducted by the NIMHANS, one in every 20 Indians are suffering from depression in India and 1 in 40 from past depression respectively. The main reason of death among teenage girls and women in India is suicide. Suicide rate in India stood at 36.6% of suicides in world surpassing maternal mortality. 9.8 million teenagers between 13 - 17 years of age are suffering from depression and other mental disorders. One in 7 Indians are affected by mental disorder with variation in severity. Indians suffering from depression are around 56 million. The proportional contribution of mental disorders to the total disease burden has doubled since the year 1990 (The burden of mental disorders across the states of India; The Global burden of disease study, 1990 - 2017).

Lately we can see progress in awareness on mental health with efforts from various stakeholders. This include concerned authorities, professionals, NGOs and other stakeholders. Especially with people themselves shedding inhibitions, coming forth to seek help and support. Thus, sharing their experiences with mental health issues have all contributed a lot in changing people's perception towards mental health. Acceptance and the importance of mental health is being embraced. It is now growingly realized that it is not just the physical health that keeps one healthy and sound. Infact our mental health along with physical health keeps us physically active and mentally sound. A balance of

mind and body enable to carry daily activities, make decision, logically reason, cope stress and handle emotions.

According to the World Health Organization, in spite of the burden of mental illness, the response of health systems towards the burden of mental disorders itself is inadequate. There are insufficient mental health professionals in India with only 0.35% psychiatrists, 0.7% psychologist and social workers each and 0.12% of nurses per 100, 000 population. This is the scenario when 7.5% of Indians suffer from some or the other form of mental disorder. There is a gap between the need for treatment and the provisions available. Around 76% to 85% of people living in low - and middle - income countries with mental disorder receive no treatment for their disorder. Hence the greater responsibilities often fall on the family members who have to assume the role of caregivers. Most of the times families are the primary source of home care and support for older relatives. This contribute to services that would cost hundreds of billions of dollars annually if they had to be paid. Caregivers are therefore a critical national health care resource (Arno PS, et al., 1999).

Hence the role of family caregivers become very important. Today we see the growing importance of participation of communities. For long term recovery and effective treatment their participation is encouraged. Family caregivers play a very important role since they are the ones providing practical care, personal care and also offer emotional support in the overall process.

1. Understanding role of a family caregiver in mental illness and the related burden of caregiving

In India, families of patients with mental illness have played crucial role in providing care to them. Mental health in India had tradition of involving families in treatment of psychiatric patients. Mental health system in our country is inadequate in its resources and system. Therefore, it was out of choice as well as compulsion for families to get involved in treatment of psychiatric patients. Any family members,

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friends, or relatives (informal) providing care for a person with chronic illnesses or functional disability for at home care delivery and is unpaid is called as Family Caregiver. They are the primary caregivers but most of them do not have formal training to provide these services (Chadda, 2014). The nature and quality of care provided by the caregivers reflects on the patient's prognosis (Oyebode, 2005). As per the findings of Centre for Disease Control and Prevention in their study titled 'Stigma and Mental Illness', the status of illness of people with severe mental illness depend heavily on their caregivers since they depend on their caregivers for almost most of their needs and daily routine.

It has been concluded by many Indian researches that providing care for a relative with mental illness is distressing and burden for the family caregiver (Murthy, 2016). As per a study conducted by Anxiety and Depression Association of America, 62% reported worst physical health as a result of care giving task. Around 40% to 70% of caregivers in the same study had depressive symptoms. About 90% of people with Mental Illness are taken care by their family members. In fact most of them receive care at home along with their treatment by their families. Hence families are involved in the long - term management of their mentally ill relatives owing to chronic nature of mental illness. As a result, the weakening impact caregivers experience during the process of caring for their mentally ill relatives have become a growing concern. As shown by clinical observation and early empirical researches a caregiving role can be stressful and burdensome (Biegel DE, et al., 1991).

As per the report of national survey conducted by The European Federation of Families of People with Mental Illness, caregivers of people with serious mental illness face burden spreading across different life domains. They are affected emotionally, socially, physically, financially and face relationship burden. In another study, more than one in three family caregivers expressed that they reached breaking point and could not continue their role (Zarit et. Al., 2010). Researchers have therefore come to conclude that the result of taking care of mentally ill family members on caregiver as unwanted and negative experiences. The caregivers may have not experienced above otherwise (Ayalew et. al., 2009). High prevalence of psychological morbidity and burden of care have been found amongst family caregivers for persons with mental illness (Udoh et. al., 2021). Therefore, they are at increased risk for burden, stress, depression, and a variety of other health complications (Gupta & Sharma, 2013). The effects on caregivers are complex and multi - dimensional. So how caregivers react and feel as a result of their role is dependent on different factors. A study has shown that caregivers experience one - third increase in negative health symptoms after assuming care giving responsibilities. As a result, caregivers use more prescription medication than non - caregivers (Murthy, 2016).

Chronic disorders with life time morbidity have higher burden on caregivers. For instance, burden of care and psychological distress for caregivers of persons with mental retardation, epilepsy, Schizophrenia were found to be higher (Reid et. al., 2005). Schizophrenia and epilepsy were found

to be among the most difficult mental illnesses to manage according to the results of many studies conducted (Wang et. al., 2017). Parents of children suffering from mental retardation experience great stress and go through so much of physical and emotional stress (Singh et. al., 2014). This signifies the severity of the burden and psychological distress in caring for patients with psychiatric disorders. Therefore, psychological distress and burden of care among family caregivers of persons with Mental Illness is highly prevalent and common. Cognitive dysfunction is one of the prevalent psychological morbidities. The other burden for caregivers are social, emotional, physical in nature which include time demanded, resources to be made available for treatment & care. There is need for caregivers to be regularly screened for psychological morbidity and burden of care for early identification and intervention (Udoh et. al., 2021). The study further asserts that the burden of care was higher among female family caregivers compared with males. This is supported with other studies in Ethiopiaby Ayalew, 2019 and India by Ampalam, 2012. Females are more prone to burden of care since they are naturally inclined to assume the role of caregivers for generally ill or mentally ill family members and relatives. He further adds that the female caregivers have more emotional, social, financial and relationship burden (Ayalew, 2019). Males on other hand tend to distance themselves from the stressful situations (Kok, 2017).

Although depression and stress have been the most frequently studied consequences of care giving. The consistent and comparatively large effects influenced by age, socio - economic status, and the availability of informal support was seen. For eg. caregivers who are older, low socio - economic status, and those with limited support networks report poorer psychological and physical health than caregivers who are younger and have more economic and interpersonal resources (Schulz & Sherwood, 2008). The study conducted in Nigeria also threw light on increase in age as a factor for higher degree of burden of care, which means with age the degree of burden increased. Therefore older people experienced greater burden of care because of their age related situation in life since they themselves need someone to care for them. This was similar with a study in India (Ampala et. al., 2012)

Older people assume more responsibilities in care than younger people, for example in providing for the financial, social and medical needs of their ill relatives. These older people may also be the guardians or parents of the mentally ill persons, and so tend to receive the impact of the poor health of their relatives more (Singh et. al., 2014). On the other hand, older age is typically related to depression (Reynolds et. al., 2017). If categorized specifically a caregiver experience primary and secondary stress which may lead to psychological distress, unhealthy health habits, physiologic responses, psychiatric illness, physical illness and even death in some cases. This is concluded after examination of wide range of outcome and measures. They identify duration, type of care provided and functional cognitive disabilities of the care recipient as the primary stressor. Finances and family conflict as secondary stressors (Christakis, 2006).

Caregiver's physical health are linked to factors that include the care recipient's behavior problems, cognitive impairment, and functional disabilities, the time and amount of care provided. Vigilance demand is another factor in case of a person with Alzheimer's disease to prevent the patient from self-harm if caregiver and patient are residing together. For instance, caring for a patient with dementia is more challenging than caring for a patient with physical disabilities alone. Since they require caregivers to be more vigilant. Caregivers of persons with dementia are less likely to receive gratitude for their help and support. These persons are not in such a state of mind to express gratitude for the help. Their caregivers are instead likely to experience depression and all of these factors have been linked to negative caregiver outcomes (Pinquart & Sorensen, 2007). Caregiver's physical health are negatively affected with feeling of distress and depression associated with caregiving.

It is not just the role of family as caregivers that cause distress but also because of the caregiver's perception of how much the patient is suffering. Caregivers live in close proximity with the patients all the time and see all their sufferings and struggle closely (Schulz R, et al, 2007). There are some patients who respond to illness or disability with calm and optimism while others respond with fear and hopelessness. It was found that two types of patients suffering emotional and existential distress resulted in caregiver's depression and use of antidepressant medication (Schulz R, et al, 2008). Few studies have focused on the relationship between care giving and health habits. In this regard, researchers have found evidence of unhealthy health behaviors. Neglecting their own health care appointments and eating a poor-quality diet among caregivers who provide assistance with basic activities of daily routine like toilet and eating (WFMH, 2013).

2. Challenges in the process of caregiving

Mental Health is one of the 17 goals of United Nation's Sustainable Development Goals. Since then it has been given its due importance. Policymakers are convinced that caregiving is a major public health issue with evidence on the health effects of caregiving gathered over past decades (Schulz & Sherwood, 2008). In spite of all these and their struggles and roles, we hardly hear people talking about caregivers issues, challenges and their need. Even at professional settings we do not see much help specifically for them. Providing care for a family member with a mental health problem involves long term stress.

Chakrabarti in his study titled 'Research on family care giving for mental illness in India and its impact on clinical practice; Are we doing enough to help families' highlights importance of family caregivers and also draws attention towards lack of services available for caregivers. In India, the approach of psychiatric set up towards helping families is conflicting. At one hand, the mental health practitioners recognize the need to involve families in treating the patient but fail to recognize the distress of this important stakeholders of treatment process (Rao, 2005). This shift in approach has proven effective significantly for the patients (Johannes, 2019). But in this effort to provide for holistic and effective care for the patients, the caregivers at home have been neglected. They are not professionally trained nor

do they have knowledge about the illness either. The caregivers in the process face many challenges and have to make major changes in their daily routine. Some struggle and even break down in the process of providing care which can increase the problem for both the patients and the caregivers

In the countries belonging to Middle East, providing care to people with mental illness is more of cultural obligation though also a culturally appreciated practice (Jones et al., 2009).

The study titled "Stigma and burden of mental illness and their correlates among family caregivers of mentally ill patients" highlighted different dynamics of caregivers and mentally ill patients' relationship. One of the female respondents who was a caregiver for her spouse described her situation as similar to the "walking dead". The highlighted important dynamics included firstly lack of knowledge. Many caregivers were shocked when their family member/ a relative got diagnosed with mental illness. They did not know how to respond and assume the role of a caregiver and many were found to be in denial. Lack of understanding by caregivers was increased by their patient's lack of insight. This resulted in difficult family dysfunction and distress. The study further highlighted caregivers concern related to inability to work leading to financial concerns as a result of high medical costs associated. Safety issue of caregiver was another concern because of high risk/unpredictable behavior of patients.

In a study, a 61-year-old sibling compared her experience as similar to a donkey carrying a heavy load. She had spent 33 years in caring a relative with mental illness. In her exact words she reported: *"What does it resemble in life? I mean it resembles a donkey. Yes. It will be constantly loaded but will not say anything, because it cannot say anything. The most it can do is to give a saddened look with its beautiful eyes. That's all. I mean its eyes are always sad; donkeys have the world's most beautiful eyes. But it is always sad, always destitute. Because it always carries a load"* (El-defrawy et al, 2000).

Another concern of caregivers was their 'concerns and doubts' about the future with regard to what would happen when they are not around or unable to care for patients (CDC, 2015). Suicide has also been option for caregivers because of unbearable burden/ high stress. Adding to the already heightened problems of caregivers is the stigma surrounding the illness. People have their own misconception and misinformation regarding the illness and leading them to behave in certain manner. The effects of stigma are manifold and worsen the situation. Stress resulting from providing care to relatives with mental disorder has resulted in suicidal thoughts as well (Jenkins et al., 1999). Misinterpretation about mental illness has resulted in experience of stress and encountering stigmatizing behaviors (Bellido et al., 2017). Care givers have also expressed their high need for professional help especially in sensitive issues of marital relationship. It was found there were such caregivers who had to take pills to be able to sleep because of distress resulting from caregiver's role (Hardy's et. al., 2011).

Lack of professional support and educational materials resulted in poor understanding of the illness (Sanden et. al., 2013). Hence informed professional support can come to their rescue and play a crucial role in improving their experiences. In fact, it can do wonders in such distressful times. But on contrary many respondents expressed lack of professional support from health care workers which is unbecoming. The study suggests that many caregivers were unaware about the illness & its characteristics, methods of treatment, ways to manage such behaviors. Lack of professional support in such circumstances further resulted in increase in burden on caregivers. Poor communication by healthcare professionals further increased the burden on caregivers. Those caregivers who revisited the mental health service on regular basis and educated seemed hopeful and positive about using healthcare services (Hardy et al., 2011).

Family caregivers have been subject matter of several literatures such as books, articles, editorials etc. But in clinical practices, the need to support and strengthen family has often been neglected. In a developing country like India, the task may face various challenges because of difficulty in collecting required data due to its varied socio - cultural set ups and backgrounds of masses. Also in clinical settings not much use of the researches in order to help families in distress is evident in their day today clinical practice (Chakrabarti, 2016).

3. Conclusion

The progress in research in this field would enable mental health professionals in building a true partnership with families providing care for those with mental illness. It is now important that they be seen as important stakeholder in the entire care giving process and cared for as well. Its time that we stop just looking at them with sympathy but instead involve them, understand them and enable them. The burden cannot be just passed on to their shoulder who are lay men with no professional knowledge and preparedness for such situations. It is important to enable them, create awareness, prepare them to carry the responsibilities. Most importantly to enable them to cope with stressful situations. Simultaneous holistic care for both patient and caregivers need to be provided to strengthen the care giving process. This would also prevent caregivers themselves from turning up as patients. Therefore, it is a necessity to have sufficient data on caregiver's issues by conducting studies on them. Later based on the findings of researches, adopting solutions in routine practice and in clinical settings is a necessary step to intervene caregiver's issues.

The prevalence of burden and distress among care givers of mentally ill patients are undoubtedly high. Many countries including developing countries like India have acknowledged the family based interventions in reducing negative care giving outcomes. Therefore, providing support to care givers is undeniably important which is a necessity rather than a luxury. But what is important is that it should be in ways which are culturally accepted, suitable, adaptable and accessible. It goes without saying that much more research is required in this area so that mental health professionals in this country are able to find effective ways to help families cope with the adverse consequences of care

giving. Timely intervention is necessary for family caregivers as well to identify their burden. Necessary help to enable them to cope effectively is equally important. Their significant role especially in absence of adequate mental health facilities in our nation and the world cannot be denied or neglected.

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