
Families Living with Mental Illness

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ABSTRACT

Mental illness is a growing reality of our times. Usually in a typical Indian family, the parents act as the primary caregivers for the child suffering from mental disorder. For adult sufferers, it can also be siblings or offspring, and at times even spouse or partner. Research on the experiences of families of mentally ill people has been minimal in the Indian context. This study aims to shift the focus from the mentally ill patients to the suffering of the caregivers and families of the patient keeping in mind the interconnected well being of the family in a collectivist culture. Following a qualitative approach, narratives have been taken from the family members of mentally ill (narratives of 8 families with mentally ill person) and also the mental health professionals (two) through semi structured interviews. The findings suggest that the family members suffer from a significant amount of stress accompanied by burden. Also, they feel secluded from the society and experience a lack of assistance to deal with the mentally ill member of the family.

Keywords: *Family members and caregivers, Qualitative Approach, Mental Illness*

Throughout the existence of humankind, researchers, scholars and even the members of the society have been fascinated by the endless capabilities of the human mind. Like any other organ of the body, however, there are times when our brain also ‘malfunctions’, not functioning in desired manner. Termed loosely as ‘mental illness’, the response of the society and family is much different than what it is to a typical physical illness, and manifests itself as frustration, anger and at times abuse. Mental illness, the ever persisting problem that causes severe anxiety and stress, is widely misunderstood. The impact and effect of mental illness on the sufferer are well known, what is less known is the consequences of the same on the family and their often invisible but tremendous role.

In a collectivist culture such as India the primary care giving roles for the mentally ill are taken up by the family. For children, it is usually the parents that take up the role. For adults, the role can be extended to siblings, spouse/partner and even off springs in case of old patients. The

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mental illness alters the roles played by the family members more as the caregivers. These changes are often traumatic and the situation forces them to accept such roles.

Interestingly though, the professionals are unskilled or unprepared to deal with the families deal with the crisis. Most of the professionals possess a great knowledge about the mental illnesses and at times even about the families but rarely they are able to devise that knowledge and understand what the family really goes through. A difference in the perception of the situation and needs has also been noted in several studies. (Hatfield et al. 1982; Spaniol and Zipple 1988a)

The skills acquired by the professionals often fail to provide the right assistance and support required by the caregivers and the family but is adequate enough to support the patient. On the contrary, the environmental factors causing mental illness also blame the families in causing the mental illness of their family member which indeed makes the caregivers question themselves.

The survey conducted by California Alliance for mentally ill on graduates in mental health discipline found that 53% of the training programs teach the theory that states family causation of the mental disorder. (NAMI Training Matters 1991). This paper will focus on the experiences of the family members and the impact of the illness on the caregivers and the family as a whole

The families of the patient suffering from mental illness experience difficulty adjusting with the illness and recovering that might even last for several years. (Terelsen 1987; Tessler et al. 1987). The family goes through shock, denial, anger, depression, coping, acceptance and finally affirmation when confronted with trauma of mental illness in the family. (Power and Dell'Orto 1980; Vander Kolk 1987).

As the families lack knowledge and clarity about the mental illness, it results in a constant cycle of emotions between hope and despair. These feelings at times might seem to be excreting and confusing yet they are experienced by most of the caregivers and family members. During the early stages, family members experience guilt, self blame and embarrassment and require help from an understanding and knowledgeable professional. Families often exhibit a strong reliance on the mental health professional hoping to seek their answers. The initial phase can be summed up as highly traumatic and confusing state for not just the patient but the for entire family.

For the person suffering from the mental illness and the care givers, life can be unpredictable and chaotic. Symptoms might exhibit themselves one day and disappear the next. New behaviors develop frequently. This makes the caregiver feel powerless and helpless to do anything. They only get worried and various aspects of the person's life change drastically.

“In a study conducted on 362 caregivers of patients suffering from serious mental illness like schizophrenia, 63% stated that they almost never have time to pursue their own activities as they

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are busy care giving.” The mental illness interferes so much so that it even becomes difficult to take a vacation due to the care giving responsibilities.

The mental illness not only affects the health of the person diagnosed but also that of the caregiver. The care givers have been diagnosed with much higher rate of stress and are twice as likely to develop anxiety related disorder as seen in the normal population. The feelings experienced by the caregiver change over time with the state of the mental illness of the patient. In a narrative the caregiver stated that “ The mental health of my daughter has also affected my mental health in a major way. Even when I am happy, I am constantly worried about what challenge might come up next and it leaves me constantly traumatized. There is almost always an atmosphere of stress at home.”

Mental illness does not only affect the everyday life and health but it also impacts the social relations of the patient and the caregiver. In a collectivist culture like India, people seek support from their close friends and relatives when they are exposed to a crisis like situation. But the response of the family members to “mental illness” can be a lot different than any other serious problem. The air of stigma, discrimination and the lack of understanding by the society very often forces the caregivers and the patients to conceal the mental illness. The fear of not disclosing it often leads these families to distance themselves from other friends and relatives and even the wider community which in the end leads to social isolation and social exclusion. In this situation, the families can seek help of support groups that consists of other families that have gone through a similar experience.

“I felt sad when I could not tell my close relatives what our family was going through because I thought they would not understand. Everyone is very supportive when it’s a visible serious physical illness like cancer but it’s not yet the same with mental illness. Mental illness is still a taboo in the society and no one really understands it”

The mental illness also manifests its impact on the financial security and the employment of the caregiver. This is usually because the care giver has to invest a lot of time caring for the patient and as a result their career suffers and takes a backseat. The job of care giving demands a lot of time and also the need to take up the responsibility of someone who is not financially independent. In certain cases, the resources needed to professionally treat the mental illness are also very expensive and not all families are able to afford it. In total it has a profound impact both in short- term and long- term on the financial security of the family. Since, mostly the role is taken up by women; their career is affected particularly more. The productivity of the caregiver as an employ also reduces significantly due to anxiety caused by mental illness in the family.

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Caregiver burden can be defined as the emotional response of the caregiver to the condition of the patient. In a research conducted by Oldridge and Hughes (1992), it was reported that psychological distress in the caregivers was twice as high as that observed in the general population. Another set of researchers Potasznik and Nelson (1984) stated that the caregiver burden could be reduced by increasing the social support provided to the caregiver and the family. Caregiver burden also affects various other aspects of the caregiver's life; for example, their marital satisfaction. Depression is also common among the caregivers. As stated by the stress proliferation model, care-related stressors might get converted into emotional distress.

Caregivers also develop certain strengths by their experience. Lefley (1990) discussed certain strengths in caregivers dealing with the mentally ill such as maintaining the balance between multiple needs and roles, easily able to overcome negative emotions, attitude and fear, trying to maintain family stability and supportive relationships.

METHOD

The study focuses on the effect of mental illness on the entire family as a unit and not just the mentally ill patient. The question addressed was the experience of the family and the changes that occur due to the mental illness.

The sample size of 10 was taken. The sample consisted of 8 caregivers of patients with clinically diagnosed depression and 2 mental health professionals. The caregivers included 3 parenting couple (age: 35-50 years.), 2 children (age: 20-25 years.) and 3 spouse/partners (35-50 years.) All of them belonged to Delhi and NCR region and were from a middle socio-economic background. The two mental health professionals had 12+ years of experience in the field. The families and professionals were approached in the hospital and later timings were fixed for the interview. Both the families and mental health professionals were informed about the studies and their consent was taken.

Procedure

The families or caregivers and also the mental health professionals were approached in the hospital and after their consent, the interview was scheduled as per their convenience. During the interview, preliminaries were taken and a small rapport formation session was carried out to ease out the interviewee. Semi structured interview that focused on the experience of the families was carried out. Narratives from the interview were collected and analyzed to extract common themes and unique experiences of the family members and the professionals. Life-story approach (Riessman; 1993) was used to analyze and extract the common themes and unique experiences from the collected data.

Ethical Considerations of the Study

1. Informed written consent was taken from all participants.

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2. Confidentiality issues were clarified. All participants were assured that their identities would not be revealed.

RESULT

The objective of the study was to assess the issues and experiences of the family members coping with mental illness. After the careful and repeated analysis of the narratives, certain common themes emerged which are presented below in Table 1. The state of denial in families when made aware of a family member having an illness was observed in majority of the cases. Dilemmas due to the unpredictable and difficult behavior were also observed. In the initial stages, the families felt helpless and disappointed. The mental health professionals agreed to the fact that adequate assistance is usually not provided to the families. Another unique observation made was the difference between the perspectives of the family and the mental health provider regarding care giving. These results were very similar to other studies concerning the experience of families of the mentally ill. (Bloch et al, 1995).

Table 1: Main themes by the perspective of the caregivers

Initial phase of denial, anger and final acceptance when confronted with mental illness.
Feeling of powerlessness due to unpredictable behavior.
Increased level of stress that affected various aspects in life.
Isolation from relatives and friends.
Fear of being labeled and stereotypes attached.
Phases of hopelessness.
The idea of responsibility of the family as a whole.

DISCUSSION

Each of the themes that emerged were further analyzed and supported by the narratives provided by the family members and professionals themselves.

When the families are informed about the existing mental illness in one of the family members, they experience great stress and trauma. The acceptance of the illness does not happen immediately. Families go through phases of Shock, anger, stress, denial and finally acceptance. The lack of clarity about the mental illness and the process of recovery make it even more difficult for the families to accept it. The families go through the cycle of hope and despair. It is usually a tough, confusing and exhausting phase for the family. The early stages of coping and recovery also accompany embarrassment, severe guilt and the fear of being labeled. Very often during diagnosis, the families are asked questions about the disturbances in the family environment, confirming to the causal theory of mental illness that puts the family members into guilt.

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Narrative provided by a daughter of the patient suffering from depression is as follows *"in the initial phase of the illness, my father would not get up from the bed and would stay in a dark room the entire day, he would refuse meeting anyone or going to work. We thought he had some work related stress, his behavior did not change over days and got even worse, he was easily irritable and would not talk to anyone. When we finally approached the psychologist, we were told that he suffered from severe clinical depression, though we were aware what depression was, we never thought someone from our family would go through the same."* This finding was similar to the findings of the study by Power and Dell'Orto 1980 & Vander Kolck 1987 where they described the typical stage that the families go through when confronted with a traumatic mental illness.

Families also seem to go through a lot of chaos and uncertainty. There are new behaviors that emerge every now and then and the behaviors that were unthinkable a week ago become the 'new normal', the families feel powerless and helpless, they feel they have no control over the situation and can only worry. *"At a point in time, I could not leave my daughter alone in the room as she would start scratching herself out of frustration, at night I would wake up to her crying loudly and screaming, at times when we would ask her why she was crying she would say she does not know"* stated the mother of a 17 year old recovering from severe clinical depression. At this stage, assistance from a knowledgeable mental health professional is important to guide the family to cope up with the everyday challenges that they experience regarding the patient. Unfortunately, it was found that the mental health professionals are not trained enough to provide the right assistance. During the interview a private clinical psychologist said *"the system is not developed enough to welcome the families. We are only guided to treat the patients and when we are asked to help anyone other than the patient, we do not know what to do. We do not even try to welcome the families because we are not trained for it. At times when families come to me they just want to be heard."* At the same time, the professionals also felt that it becomes difficult to work with families as they seek instant results and want the mental health professionals to take the role as the primary caregiver of the mentally ill (Fisher et. al;1989). *"In my 15 years of experience as a clinical psychologist, people come to us with patients because they are seeking immediate relief, they fail to understand that we are not magicians and it takes time to recover from the mental illness. They pay us for giving instant solutions which is almost impossible in case of severe mental disorders. If we say anything against this belief, they just do not accept it."* The family members stated that they felt better in the company of people going through the similar experience. Potasznik and Nelson (1984) found that the increase in satisfaction with the support network resulted in drastic relief in objective and subjective burden among the family members.

Very often, the families have to gain knowledge and education about the mental illness themselves to get a clearer insight of their role as a voluntarily caregiver. Gartner and Riesman (1982) have elaborated upon the importance of mutual aid and self help groups organized by the

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families themselves. Feelings of stress, anxiety, guilt, fear are very common among the family members. In a research it was found that caregivers of the mentally ill are at twice the rate of developing anxiety related disorders. Stress-Proliferation model shows concern with the changes of conversion of stressors related to care giving into emotional distress.(Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). According to study conducted by Rolland in 1994, it was found that in mental disorder such as depression and other mental illness; there is increase in the strain on the family caregivers due to exhaustion and the continuous need and addition of care giving tasks. The family members were always “on call” to deal and cope up with the crisis of the mental illness that affected on a day-to-day basis. The feelings keep changing with time and the condition of the mentally ill. The care givers lose the sense of their own individual life because they spend a significant amount of time playing the role of care giver. In a narrative provided by the wife whose husband was diagnosed with depression 2 months back she said ***“I am unable to pay attention to my children and my daughter who is in her teens feels neglected as I spend most of the time taking care of my husband. My husband has stopped going to the office and is always at home and usually always in his room. At times he wakes up in the middle of the night, worried and I have to stay up with him. This is a job you just cannot take a break from.”***

Usually, when people are diagnosed with physical illnesses such as cancer, the family and friends provide significant support. Unfortunately, that is not the scenario in the case of a mental illness. The lack of understanding of the mental illness among the friends and relatives restrict the family of the mentally ill from disclosing the information. They often feel that they might be labeled and bad mouthed. It was found that in most of the cases the families were hesitant to even approach the mental health professional because they thought it would automatically defame them. The family members themselves accepted that if they would not have experienced it themselves, they wouldn't have understood how serious mental illness can be. This fear leads them to isolate themselves and the patient from the wider society and forces them to face the issue of isolation. A mother stated ***“It has been 3 months and we have not yet disclosed it to any of our relatives that our daughter suffers from depression. We do not yet know how they will react to it. We avoid going out as much as we can as she is easily irritable and breaks down very often. We do not want them to find out something is wrong. Once, my brother came home but we had to take her to the doctor, I told him that we were going to see a close friend. We just don't want anyone to label her as a ‘retard’.”*** Mental illness also has a serious impact on the financial security and the career. It is a time demanding job to provide care to the family and also the therapies are expensive. It was observed, in most of the cases, the women were the primary caregivers and had to compromise with their job. Nonetheless, the stress at home due the illness also affected the productivity of other members of the family, regardless of their age or gender. ***“I had to quit my job so that I could pay attention to my child, I think it was my fault that he felt low and I decided to pay more attention to him and take care of him.”*** There are always phases of hopelessness and despair that families go through while fighting the mental

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illness but, adjusting to the everyday challenges due to the mental illness makes them more adaptable to any other problem that arises. (Danielson, Hamel-Bissell & Winstead-Fry, 1993) *“Dealing with my husband’s condition, made me much more resilient to any other problem that I come across now. It looks like a trivial thing and I know no matter how hard it is, it will someday pass and get better with time.”*

One interestingly unique finding of the research was, that though these families go through a lot of stress and burden due the mentally ill member of the family, when asked if they would like to send them to an institution for their recovery and rehabilitation, most of the care takers refused the idea. Even though the role was stressful and difficult, the idea of separation was outrightly refused. This indicates the strong sense of responsibility of the family as a whole in the collectivist culture.

Building a Family Friendly Mental Health System

The contributions and needs of the family and caregivers living with mental illness should be recognized. The stress and overwhelming experiences that they go through should be addressed by providing them with services to respond to their questions and concerns. It should also be taken into account that they should be identified for their vital role that they play for their loved ones.

Families are in the need to access an improved level of education, knowledge and information, counseling and some respite. Accurate information provided by the mental health care professionals, service groups or families and friends themselves can ease out the fears, anxiety, stigmas associated with the illness. Educating the families about the illness can help them in developing the coping strategies that best suits them. Counseling can help in significantly reducing the stress and anxiety due to the mental illness in the family. Sometimes, social recreational programs can also benefit the families and provide them with brief respite. A lot of stress is due to the stigma and fear of discrimination associated with the mental illness, the lack of understand of the illness is the general public is leading greatly to the social exclusion. Mental health promotion workshops and anti-discrimination and stigma programs should be organized more frequently that it is at present. Such workshops should also be organized at both the levels of workplace and the service sector.

The impact on the productivity of the care giver and other members at work reduces due to the care giving roles, to overcome this, organizational counselors should be trained to address to the special needs of such employees and ease out their burden. Other professionals and the health care staff should be sensitized to the need of the families and sensitized to work with them as equal partners in providing health care to the mentally ill.

LIMITATIONS AND FUTURE IMPLICATION

1. The sample size was small (n=10).
2. The sample was confined to Delhi-NCR region.
3. The sample size of the family members was more than the sample size of the mental health professionals which could have produced some bias in the results.
4. The difference in gender, age and experience was not considered.

CONCLUSION

The aim of the study was to understand the effect of the mental illness on the family as a unit. Families and the caregivers of the mentally ill patients play a vital role in the recovery process. The families themselves face and cope up with daily challenges. Factors such as lack of knowledge, stigma attached with the mental illnesses, and lack of support make it difficult for the families to cope up. It is important to address the contribution of the families and caregivers and provide them with a better support system and essential resources to better deal with the mental illness.

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Conflict of Interests

The author declared no conflict of interests.

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