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## KNOWLEDGE OF ILLNESS AMONG FAMILY CAREGIVERS OF PSYCHIATRIC PATIENTS

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### Introduction

In India major part of the population resides in rural areas and it has been found that about 80% to 90% of the mental disorders are undiagnosed and untreated due to lack of knowledge and negative attitudes toward mental illness (Gupta, 2014). Further, stigma and negative attitudes toward people with mental illness have been observed to be common worldwide among general population (Högberg et al., 2012).

In Kashmir region, studies on mental health have demonstrated a high prevalence of mental disorders (Me'decins Sans Frontie`res, 2015; Haq et al., 2015; Hassan & Shafi, 2013; Housen et al., 2017; Paul & Khan, 2018) and there has been a 30-fold increase in the incidence and prevalence of mental disorders in the region (Margoob & Ahmad, 2006). Earlier studies (de Jong et al., 2008) reported that one-third of the population showed evidence of psychological distress and suicidal ideation among adults. More recent studies have reported even higher rates (Housen et al., 2017). In Kashmiri community too psychiatric disorders are facing stigmatizing attitude and often met with social rejection. Traditional healers play a key role in primary psychiatric care. The majority of people live in rural areas; however, psychiatric facilities are located mainly in the city. This shortage of mental health facilities enhances the inclination of people towards the use and practice of traditional healing.

Families are the main source of caregiving for persons with mental illnesses in the Indian culture and more than 90% of patients with chronic mental illness live with their families (Chadda, 2001). But they often lack the knowledge and skills required to assist their mentally ill relatives. Traditional faith healing is usually considered for treatment of persons with mental illnesses. This type of health-seeking behaviour could be predisposed by cultural beliefs regarding the role that supernatural forces like demonic control, black magic, and the evil eye play in causing the mental illness. Moreover, the patient admission to a psychiatric hospital produces a stigmatizing label not only for the patient but also for the family.

The caregivers take care of the day-to-day needs of the people with mental illness, monitoring their mental state, relapse and deterioration. However, the lack of knowledge and low mental health literacy pose challenges to family caregivers, mental health patients and service providers (Mohamad et al., 2012). Mental health literacy has been defined as knowledge and beliefs about mental disorders, which aid their recognition, management or prevention (Jorm et al., 1997). Further, researchers have suggested that mental health literacy is not a single dimension but rather represents knowledge and beliefs about mental health disorders that emerge from general pre-existing belief systems (Griffiths et al., 2009). However, much of the literature has found that mental health literacy among the public is poor (Furnham et al., 2011).

Shinde et al., (2014) has contended that due to insufficient knowledge and caregiving skills, family caregivers may be unfamiliar with the type of care they must provide. They require a basic level of knowledge about mental illness and how to access help for ill relatives (Bland & Foster, 2012). Knowledge of mental illness among caregivers is a crucial building block to develop the skills necessary to manage symptoms outside the mental health facility. Appropriate skills are important to help family caregivers maintain a healthy lifestyle, recognize early warning signs of relapse, and act promptly to manage stressful situations (World Health Organization, 2013). Family caregivers need to know the expected outcomes of the disorder, as well as challenges that may arise during shift from hospital to the home environment. Studies have shown that inclusion of families in the planning and care of ill relatives has a strong impact on mental health. Family involvement has been reported to improve health and recovery, reduce the risk of a relapse, and increase family wellbeing (Ibrahim et al., 2015; Lehman et al., 2004). A study by Rugema and associates (2015) found that unawareness of illness among caregivers was associated with lower use of coping strategies and frequent resignation. There is evidence that shows the more information family caregivers have, the better they can put the illness in perspective (Mohamad et al., 2012). This study is therefore aimed at exploring family caregivers' knowledge about mental illness and to suggest self-management program to support and improve the caregiving process.



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Furthermore, no ample published research is available on mental health literacy among caregivers of persons with mental illness in Kashmir. Therefore, the present study was aimed to explore the caregivers' knowledge of mental illness in terms of their causal attributions.

## Method

Since, the present study aims to gain an in-depth understanding of the lived experiences of people who serve as caregivers for mentally ill family members, therefore a qualitative approach was considered to be more appropriate. A qualitative method was conducted using flexible methods through interviews with caregivers. Semi-structured, open-ended questions were used to encourage responses that described the unique experiences, challenges and concerns of each caregiver.

## Sample

The sample of the present study consists of the caregivers of people with schizophrenia and bipolar disorder. Caregivers were identified by self-report and by verifying that he or she assists another with at least one ADL (activities of daily living) or IADL (instrumental activities of daily living). The participation of caregivers was secured according to the following inclusion criteria:

Inclusion criteria: Participants were considered eligible for inclusion in this study if they were

1. 18 years and six months old or above.
2. Actively involved in the care of the patient and living with the patient for at least twelve months.
3. Immediate family relative (Parent, spouse, sibling, brother or sister), non-immediate family relative (Other relative) or non-relative.

The sample was drawn from the patients visiting the Institute of Mental Health and Neurosciences Kashmir (IMHANS-K) for treatment and follow up. IMHANS-K is one of the only two psychiatric hospitals in the state of Jammu and Kashmir and also the most visited by psychiatric patients.

## Tools

Interviews are used to gain insights into a person's subjective experiences. An in-depth interview was considered appropriate as the main research instrument for data collection as it allows to gather extensive information on the participants' past and present experiences. This technique allows the researcher to collect both attitudinal and behavioural data. Semi-structured, open ended interview questions were used to elicit responses that reflected the unique complexity of the caregiving experience. Semi-structured interviews characterized by open-ended questions and an interview guide in which the broad areas of interest, including sub-questions, were defined.

## Ethical considerations

At the interview, the researcher explained the informed consent, reiterating that participation is voluntary and they may choose not to answer any questions and could end the interview at any time. To safeguard confidentiality each participant was assigned a number and their names and other identifying information was removed from each transcript.

## Data collection procedure

Before proceeding to data collection, the researcher approached the Head IMHANS-K, for necessary approval. The researcher explained the purpose and requirements of the study and obtained the written approval for the same. The researcher then approached the administration to get information about the patient records, types of patients visiting the IPDs and OPDs etc. With the help of patient records, the researcher identified the cases for interview. Only those cases were chosen that were admitted in IPD because the overcrowded OPD would not have been feasible for the conduct of the interviews. Moreover, majority of the cases visiting OPDs were the newly diagnosed ones and hence not meeting the required criteria of the study. The period of stay of IPD patients ranged from few days to few weeks and most of them were accompanied by their caregivers.

Before starting the interview, each participant was briefed about the research study and their cooperation was sought for the study. The interviews were scheduled as per the convenience of the participants. The researcher interviewed eleven participants until the point of saturation. Thirteen interviews were conducted with eleven family members. The researcher did two follow-up interviews for clarification of some topics.



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## Analysis process

After transcribing and translating the interviews the researcher read through the data actively and repeatedly so as to become familiar with the entire data set. After this step the coding process started for which qualitative data management software ATLAS.ti was used. In vivo coding was used which involved labelling sections of text with the exact words used by the participants (Creswell, 2007) as well as open coding, which involved relating concepts with each other to “break the data apart and define concepts for blocks of raw data” (Corbin & Strauss, 2008, p. 198). Next stage involved the examination of the coded and categorized data to look for potential themes of broader significance. Both narrative descriptions and representative data extracts (e.g. direct quotations from participants), were used to describe the data and provide an argument for why the researcher’s explanation richly and fully answers the research question.

## Results

The appropriate skills are crucial to help family caregivers maintain a healthy lifestyle, recognize early warning signs of relapses, and act promptly during stressful circumstances. There was, however, a lack of information about the mental health conditions of the patients among many caregivers who were interviewed for the present study. Because caregivers did not know enough about mental disorders, they were confused about their constantly changing behaviours. These changing behaviours range from aggression to absurd acts to violence against family members which often cause anguish among the caregivers and family members. One of the caregivers who was caregiving his brother who was suffering from schizophrenia, reported how in the beginning the family wasn’t able to make sense of the absurd behaviours.

He tried to set fire to the house, he became more violent than before and used to beat mother also, threw stones on us. We couldn’t understand what was wrong with him and we used to get angry on him (R6, Brother, 47, Rural).

Also, caregivers were more confused about the unpredictable changes in behaviour from normal to problematic and vice versa as is evident from the following quote:

When he is fine, he takes bath himself, washes his clothes, and sometimes cooks also. But when he is not well, he keeps doors open, turns on the gas stove, throws me out of the house, keeps reading some papers. Don’t know what’s going on in his mind (R6, Brother, 47, Rural).

However, those caregivers who took time to find out about the person’s illness and what to expect seemed to understand the mental illness better and provide better care also, than those who were uninformed and perhaps unwilling to accept the person’s mental illness, as is indicated by the following quotes.

My son checks out from the internet. Ten years back he felt that there is someone inside him but it was his mental condition nothing else which could be treated by medicines. We can’t say that there is only depression or stress, but mental illness has so many types. (R4, Daughter-in-law, 47, Rural).

One thing that I would like to tell you mam, this illness has affected almost every family in Kashmir. I have seen people who feel shame, they don’t talk about it but we don’t feel shame. We don’t have to be ashamed; it is an illness which needs care (R4, Daughter-in-law, 47, Rural).

As evident the from above quotes, acceptance of problem and willingness to take care of the patient empowers the caregivers to better manage the condition of their patients. Moreover, caregivers who were literate, had resources and support from other family members seemed to understand and manage the condition in a better way. Such caregivers also felt less burdened. Furthermore, caregivers who have sufficient knowledge and skills to deal with the mental illness often benefit others with their experience. Once the caregivers have understood the nature of illness, they then guide others with similar issues. This experience sharing often proves beneficial to those in need.

We now guide people regarding this illness which is called counselling. I will give you an example of a girl in our neighbourhood who used to wash her hands repeatedly. I suggested her family to take her to doctor and she was cured. Today she is doing fine and they bless me. Her sister-in-law would keep her children away from her. Another woman used to self-talk. We are now well aware because of our experience we often see such patients here. I brought her here 2-3 times for consultation, now she comes on her own (R4, Daughter-in-law, 47, Rural).



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There were a few cases where the caregiver thinks that the patient is pretending to be ill

I am asking them to shift him to the closed ward and set me free. I also said in the court to keep him closed and neighbours also said the same in court, but they said that he is mad take him to mental hospital. but he is not mad, if we keep coming here even for ten years, he will not be fine (R5, Sister-in-law, 34, Rural).

The caregiver seems to be very troubled by her role and wants to get rid of the patient. This may be because of the symptom severity, dangerous behaviour of the patient and also because she believes that the patient is deliberately troubling her and her family.

It is important to mention here that the patient is not her first degree relative and she has not taken the caregiving role by her choice.

This caregiver further explains the patient's suspicious behaviour in this way

He eats well and on time and after finishing his meals he creates troubles for us. All his tests are normal. I feel that he does everything deliberately.

The perception about the causation of illness not only reflects caregivers' attribution of what might have caused the illness but also their surrounding which they partly if not solely held responsible for their illness. Causal attribution is a crucial aspect in the care of patients with mental illness as causal beliefs plays significant role in determining what causes the illness and the kind of care that need to be sort to mitigate the suffering. Understanding the personal perceived perspectives of the caregivers on the causation of the illness can help us to understand and explore the factors that may potentially affect the treatment seeking decisions taken by the family members as well as towards the successful treatment outcomes. However, such kind of attribution had not been arrived at by mere speculations rather such understanding was borne out in their discussion of the range of experiences that they brought to the discussion about their ailing health. In the present study, the causations attributed by caregivers can be broadly categorized into supernatural factors, environmental factors and biological factors. However, supernatural causation was found to be more prevalent belief compared to other factors. Black magic, curses, spiritual forces and medicants are the supernatural influences that were held responsible for mental illness.

He was normal in his childhood, don't know what happened to him. He started hating us, don't know if someone has done some black magic, can't understand (R5, Sister-in-law, 34, Rural).

A 50-year-old mother widowed at a young age whose son is diagnosed with bipolar disorder and other son lives separately, responds as follows

I'm not sure. I suspected my sister-in-law but I don't have proof. I doubted she might have mixed something in his food as he used to go to her house (R2, 50, Mother, Rural).

She also thinks that some supernatural power may have affected her son while he was in her womb

When I was expecting, I went to a sufi's (ascetic) grave, there a mendicant gave me something to eat, maybe that might have affected him (R2, 50, Mother, Rural).

Another woman cited the spiritual force as responsible and put it in this way

He used to recite Quran and offer prayers. He had a spiritual guide who had given him wazifa (recitation of supplications) to recite. With that he went on to become like a mendicant (R9, Sister, 55, Rural).

A sister-in-law who has been single-handedly handling the patient as well as looking after her house and her children blamed the patient and said

He is not ill. He is cursed by his parents; he did no good to them. He was not with them even at the time of their death (R5, Sister-in-law, 34, Rural).



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The caregiver's husband is a labourer, working away from home most of the time. They have six children and seem to struggle with their daily expenses. She is a caregiver by chance not by choice. Caregivers' own life challenges, responsibilities and relation with the patient seem to determine their attitude towards the illness and the patient. Mothers and siblings attributed the patient's illness to external factors while other relations blamed the patient.

It is evident from the above quotes that cultural beliefs have a major influence in understanding of the illness. The different supernatural causes mentioned by caregivers are quite common in everyday life and are a part of Kashmiri culture. Moreover, the attributions stated by the caregivers are internal and not external because these are formed by the caregivers and not the patient himself/herself.

Other causations endorsed by caregivers were biological factors such as brain dysfunction, heredity and childhood temperament. For instance, a 65-year-old father whose son is suffering from bipolar disorder says

It's some nerve of the brain. I told doctor to check his brain and see what is wrong (R7, Father, 65, Rural).

A 70-year-old mother caring for her 50-year-old son said

As much as I understand he has a problem here [pointing towards head], otherwise there is no disease in his body. This condition does not let him eat or drink properly, eats dirty food, sits at dirty places which indicates that his brain is not working isn't it? (R8, F, Mother, 70 years, Rural).

Pointing out the hereditary factors, a 45-year-old divorced woman whose younger brother is diagnosed with schizophrenia states.

Our elder sister also has some problems like suspiciousness, mother also used to remain sad all the time she never was interested in home. Sister's engagement was cancelled because she continued to do weird things. (R11, Sister, 45 years, Rural).

Some caregivers believe that childhood temperament has persisted and impacted the adult life of the patient

He was ill-tempered since childhood. He would argue and fight if he didn't get what he wanted (R2, 50, Mother, Rural).

Environmental factors such as unemployment, family conflicts, failed relationships were also listed by few caregivers

He had an affair with his batchmate and Allah knows the rest (R2, 50, Mother, Rural).

Sometimes it happens when there is conflict between father and son over property, or if one is unemployed tension develops or if there are family conflicts (R6, M, Brother, 47 years, Kupwara).

An unmarried caregiver sister stated the failed marriage of her brother as the cause of his illness and reconciliation as the possible cure

I mean if his wife returns back to him, his illness will end because he is shocked by her betrayal, she married another man and now lives in our locality (R9, Sister, 55, Rural).

## Discussion

Very little is known about the caregivers' knowledge and attitude toward mental illness in Kashmir. The present study thus attempted to investigate the caregivers' mental health literacy factors such as knowledge and attribution of illness. The results of the present study show poor knowledge about mental illness among caregivers. This finding is similar to study by Lehman and colleagues (2004) that reported that most of the participants had no prior knowledge about the disorders of their relatives. The caregivers in the present study demonstrated their knowledge of mental illness by citing different causes of it. Majority of the participants cited supernatural forces as the cause of mental illness. Other cited causes were biological and environmental factors. This finding is in line with the study from India which has demonstrated peoples' belief in supernatural powers as the causative agents of mental illness (Kishore et al., 2011).





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Educational level, socioeconomic status, the residence of the caregivers in addition to patients' behaviour are the factors that influence caregivers' literacy and attitude towards mental illness in several studies (Das & Phookun, 2013; Mehrotra et al., 2018). In the present study, education was a significant predictor of caregivers' knowledge and attitude towards mental illness, where non-educated caregivers had poor knowledge and negative attitude towards mental illness. Similar findings were reported in research studies, for example literate respondents were seven times more likely to exhibit a positive attitude towards the mentally ill as compared to non-literate subjects (Kabir et al., 2004). In another study respondents with a high level of education had a favourable attitude towards mental illness and believed that the etiology of mental illness is biological and not God's punishment (Madianos et al., 1999)

Majority of the participants were females and mothers and this finding is similar to other family caregiving studies (Mohamad et al., 2012; Ae-Ngibise et al., 2015; Oheari, 2001). This has been attributed to mothers being traditionally more involved in the caring role.

In developing countries, when individuals develop a mental illness, they are most likely to be cared for and live with their family of birth (Oheari, 2001) This could explain the finding in this study that most relatives were first degree relatives, especially the patients' parents.

In addition, educational level, socio economic status, family support made it more likely for individuals to and accept a biological basis for mental illness, understand the diagnosis better and provide a better care which ultimately resulted in better attitudes.

## Conclusion

This study explored the knowledge of family caregivers about mental illness of their relatives. Poor knowledge and lack of access to information about illness complicates the caregiving process, and impedes their wellbeing. Mental health professionals should provide necessary information in a clear and understandable manner. Education on the illness trajectory should be tailored towards each family caregiver's understanding and level of education. Information about the disease, role of medication in controlling symptoms of the disorder, side effects of medication, types of treatments, and support strategy should be provided. This type of information can relieve family caregivers' distress arising from uncertainties about their relatives' behaviour. There is an urgent need to educate and change the attitudes of the caregivers regarding mental illness through mental health literacy programs Further, mental health professionals should take active role in educating these specific populations.

Psychiatric institutions should provide educational programs to family caregivers of mentally ill patients to improve their knowledge and attitude towards mental illness and to enable them to cope with the aggressive behaviour of the patient. Thus, it is highly recommended to increase public awareness about the nature of mental illness and its management that could promote seeking psychiatric care from the start and decreasing the role of traditional healers.

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