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Original Article

Stigma and mental health- caregivers' perspective: A qualitative analysis

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ABSTRACT

Background: The caregiver burden for mental health is found all over the world and almost eight out of ten caregivers face it when providing care to the mentally ill person, as the illness is challenging and chronic in nature. Stigma due to mental health contributes to increase in the burden of caregivers.

Methods: A qualitative research methodology was adopted to understand the perception of caregivers of mentally ill patients. In-depth interview of 20 participants was conducted who were the caregivers of mentally ill patients in the hospital.

Results: From the perceptions of caregivers, we have derived four themes under which the perceptions of caregivers are described.

Conclusion: We can conclude that stigma towards mental health in the society is a burden for caregivers when taking care of mentally ill patients and it is obstructing overall mental and physical well-being of the patient.

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1. Background

The main caregivers of the mentally ill person are the family members^{1–3} in most of the eastern part of the world. More than nine out of ten mentally ill persons live with their families in our country.² There is growing attention given to the caregivers who have been associated with the mental health services over the past 10 years.^{4,1} Caregivers play various roles in everyday care of the mentally ill person, e.g. monitoring their mental state and treatment, accompanying them to the hospital or clinic, offering emotional support, helping them economically, etc.^{2,5} Caregivers also play a very important role

in adherence to the treatment.¹ Furthermore, caregivers have to tolerate the behavioural swings of the patient, including aggressiveness.^{1,2} Care giving along with other routine activities makes the caregiver experience negative and some of them consequently lead to substantive stress or burden,^{1,2,4} while others get adjusted to it.^{1,4} The needs of the caregivers often are the same or prevail over the needs of the mentally ill¹ and sometimes have an effect on their quality of life.⁶ The caregiver burden is found all over the world and almost eight out of ten caregivers face it when providing care to the mentally ill person as the illness is challenging and chronic in nature. The constant stress or burden has a negative effect on physical, psychological and social health of the caregivers,^{2–5}

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which may lead to burnout and emotional fatigue in the long run, and they often neglect their own health and welfare.⁵ The caregiver burden can be divided into two: objective and subjective.^{2,4} The objective dimension includes disturbed family day to day activities, limitations on leisure and social activities and economic costs, while subjective dimension includes caregivers' harmful assessment of conditions like remorse, embarrassment and annoyance. The caregivers' may perceive themselves as being secluded from the community as a result of limitations on social and leisure activities as well as social stigma and discrimination. Caregivers' burden can have either negative impact on themselves like avoidance, rejection, suicide, looking for religion,² sometimes perceiving themselves to be the contributors to the illness⁶ and performing destructive deeds towards mentally ill person or resorting to positive actions like problem solving and asking for help.² Some caregivers feel that mentally ill persons are a threat to them.¹ Caregivers are the key support system in our country and are often neglected.^{2,4} There is dearth of evidence for the perception of caregivers⁴ especially in developing countries.⁵ Hence it is of paramount significance to be aware of what caregivers and stakeholders perceive about the mentally ill persons. This study will address this issue, which in turn will help in developing appropriate interventions to address their needs.

2. Methods

A qualitative research methodology was used. In-depth interview was conducted. It was a hospital-based study; the participants were recruited from two hospitals of Udupi district, Karnataka, India. The study participants were the caregivers of mentally ill patients. The caregivers of mentally ill patients (who were getting treated or admitted in the hospital for the treatment) were recruited to participate in the study. The criteria for an eligible caregiver for the study were the participant must have been a caregiver for at least 1 year, supporting the patient emotionally, financially and above 18 years of age. Convenient sampling was used to select the participants for the study. Informed consent was obtained by verbal consent and all the interview sessions were audio taped. We conducted 20 sessions in all, with 20 in-depth interviews, and about 12 participants refused to give the interview; the reasons may be hesitation, fear, etc. All the participants were the caregivers of patients with psychotic illness (patient usually requires hospitalization or intensive treatment). Patients suffered from paranoid schizophrenia, schizoaffective disorders, bi-polar disorders, major depressive disorder and retrograde amnesia. The minimum age of the participant was 32 and the maximum age was 78. In this study, six participants had primary education, three of them had secondary education, six of them had attained their graduate degree and five of them had a post-graduation degree. The participants were from low, middle and high socio-economic status background.

Qualitative interview guide with probes was used for the interview. The interview guide consisted of the following domains such as socio-demographics, mental illness (type, duration, approach to psychiatrist, early treatment, delayed treatment), stigma and mental health, experience of stigma, need for combating stigma and preventable measures. There

was no fixed sample size; the interviews were carried out till information saturation (no emergence of new information or repeated occurrence of same information) was attained. The information saturation was saturation that was achieved after 20 interviews. The in-depth interview was conducted by trained professionals, interviewer and a co-facilitator. Role of the interviewer was to involve in the conversation, where as co-facilitator was assigned the responsibility of audio recording the conversation and summarizing entire discussion. All the participants gave consent for audio recording of the interviews. The minimum duration of the interview was 45 min and the maximum was 1 h, 10 min. Ethical committee approval was obtained by Institutional Ethical Committee, Kasturba Medical Hospital, Manipal (ECR/146/Inst/KA/2014). The data were collected anonymously and confidentiality of data was maintained.

3. Data analysis

The interview summary was transcribed onto the document. The qualitative data analysis was carried out using manual thematic content analysis. The themes for the analysis were derived through inductive approach; in this approach the themes are derived from common views shared by the participants. Four-stage content analysis was carried out, with firstly, development of a coding schedule, coding of the data, description of the main themes and linking of the main themes and then analysis of cyclical continuous process was carried out through three stages: "data reduction", "data organization" and "data interpretation". Coding of the data was performed manually.

4. Results

Overall 20 in-depth interviews were conducted. On an average, each session lasted for about 45 min. Following are the broad categories that represent caregivers' perception on stigma and mental health. Through this study we realized that the experience of stigma did not vary across education levels, and it was experienced by the people having different education levels. The patients of higher education too experienced stigma, as is evident by the following quotes. There was breakdown of families because of stigma due to mental illness. At the same time the patients in joint families felt more secured with respect to support and stress.

Perception 1. Society: Society plays a vital role in supporting families with mentally ill patients by accepting them as a part of the community. Most caregivers are parents or relatives of the mentally ill patients. These patients require their constant attention. In India, the mentally ill patients and their families are shunned by society. In India, it is common for the patient's family to hide their illness for fear of being secluded by society. This results in the patients not receiving the appropriate treatment at the right time, which in turn results in the progression of the illness.

"I'm a business man; I realized my wife has a problem after 5 years we were married, when one day I saw her smiling

repetitively without any reason. I have money, influence, contacts, but I go and wait like any other common man at psychiatric hospital of a different state. I don't want anyone to label my wife as a mental patient. I lock her inside the house and come to office. I have everything, but I am not happy. Every person should have freedom to say boldly I am visiting a psychiatrist like how they say without any hesitation that, I am visiting a cardiologist.” (55 years, male, business man)

Perception 2. Marriage/relationship: Often when the patient is diagnosed as mentally ill, years after the marriage, the spouse becomes the caregiver. Due to the stigma attached to mental illness in India, this often results in divorce or abandonment of the patient. The partner may not be mentally or in certain cases financially prepared to devote the time and attention a mentally ill patient requires. This in turn takes a toll on the marriage. Often the partner is pressurized by his/her family to break the relationship. This stress ends up in abandoning the mentally ill rather than providing the support and stability the circumstances demand.

“My daughter is 40 years old, she is suffering from mental disorder, her marriage broke, and I regret not taking her to the hospital at an early stage. We were apprehensive; society may label our daughter a mad person. Now, the severity has increased, we are very poor. I have only my daughter. We have to support each other. What will I do?” (65 years, female, coolie)

Perception 3. Unemployment: Most often the caregivers of mentally ill patients are their immediate family or their spouses. As a result of seclusion from their community, most patients especially women return to their parents for support. The parents of the patients may be elderly and unable to provide the emotional and financial secure environment the latter requires. Sometimes, the parents of patients have to take up odd jobs to make ends meet. If the caregiver is a spouse, he/she is unable to seek proper employment, as their constant attention is required by their partner. Even in certain cases, where the caregiver is financially secure, the stigma of being labelled by society as the spouse or the parent of a mentally ill person is emotionally taxing for the caregiver.

“My husband passed away 10 years ago, we have neither had any savings nor any property. I have completed my secondary education, still I cannot go for a good job as I have to take care of my son who is suffering from paranoid schizophrenia, I cannot leave my son alone at home, sometimes few people have taken advantage of his illness and have ill-treated him, we have lost some materials from home, there are instances where he has ran away from home and I couldn't find him for three days, I have an option of locking him at home but I cannot work in peace. I have no relatives or a friend to help, my life is miserable.” (40 years, female, local business)

Perception 4. Stress: The stress felt by the caregivers of mentally ill patients cannot be explained. The stigma experienced by the caregivers when having a mentally ill patient in

their family takes a toll on both their physical and emotional health. They are required to give their undivided attention to the mentally ill patients. They are socially marginalized by their community. They find it difficult to keep a job for a long period of time and are often the sole breadwinner of the family.

“I am a professor, my wife and mother-in-law are diagnosed for schizophrenia, and I have been taking care of them since 14 years. I fail to concentrate on my work, my academic travel to various places is restricted, my social life is restricted, I have to be back once I get any phone call from home. No relatives or friends would want to help us in emergencies, they avoid us. Every day the stress encloses me, I am glad that I am sharing this with you it's not even easy to share these feeling with my closed ones.” (45 years, male, professor)

Perception 5. Delayed Treatments: More often than we realize, the treatment of the mentally ill patients is delayed because of the fear of the stigma attached to mental illness in the Indian society. The caregivers are habitually in denial of having a partner/family member who is mentally ill. They fear being isolated from the society and destroying their family name and status in the community. This results in the patient not receiving the required treatment at the right time and thus results in further deterioration of his/her mental health. This unfortunately worsens the physical, emotional and even financial condition of the caregiver.

“I used to notice unusual behavior of my daughter since she was 12; sometimes sad, at times talking more and irrelevant things, talking to herself, deterioration in her academics, and loss of interest in her work. I neglected these aspects for 10 years, I gave importance only when disease had progressed and when it was uncontrollable. That was a biggest mistake, had I consulted the doctor before, she wouldn't have reached this state. The biggest obstacle for this was fear, stigma and people.” (42 years, male, private company employee)

5. Discussion

Using standard methods of qualitative research helped us to gain in-depth insight on the stigma experienced by caregivers' of mentally ill patients, which is the biggest strength of the study. We could understand the different forms and nature of the stigma. Interpretation of perceptions of family caregivers' of mentally ill patients is characterized by stigmatizing behaviour of society, stress experienced by caregivers, difficulties to get assistance and unemployment; broken marriages of mentally ill patients increase burden for ageing caregivers and delay treatment due to stigma that increases the severity of mental health disease among the patients. The overall interpretation of perceptions is depicted in Fig. 1. One of the studies on mental health caregivers and their physical health shows that there is significant association of mental health burden with caregivers' health problems.⁷ A qualitative research on caregivers of schizophrenic patients suggests that

Fig. 1 – Schematic presentation of caregivers' perception on mental health.

caregivers perceived education as an essential component to help combat stigma in the society due to mental illness.⁸ Another study reports the difficulties of family caregivers for seeking help when the patient is instantly unwell due to confidentiality of the issues due to stigma.⁴ One of the researches implies that the caregivers perceive that long term association with mentally ill patients is associated with stress and emotions such as “shame, embarrassment, feelings of guilt and self-blame.”⁹

6. Strength and limitations

The present qualitative study address a sensitive and an important topic related to caregivers' perception on stigma. The study has comparatively included a large number of in-depth interviews with caregivers of mentally health patients admitted in two psychiatric hospitals of Udupi district. A limitation of this study is that there were several potential selection biases while recruiting caregivers of mentally ill patients. Only around 50% of the caregivers of patients gave consent to participate in the study. The caregivers from the hospitals were only selected for the study.

7. Conclusion

From the perceptions of caregivers, we can conclude that stigma towards mental health in the society is a burden for caregivers to take care of mentally ill patients and it is obstructing overall mental and physical well-being of the patient. This study may help designing more sensitive services for mental illness. The society should rather support the caregivers than stigmatizing. Possible approaches are necessary to be carried out for training of caregivers to use essential coping skills. Support groups can be created to meet the needs of caregivers and mentally ill patients. To educate the population on treating mental illness as any other disease is of prime importance. Policy legislations are required to address the caregivers' needs. The limitation of the study is that the results of the study cannot be generalized to the whole

of India as the results are based on 20 interviews. But, we would certainly recommend such studies to be carried out across the different places of the country, which may convince the policy makers to provide attention for the care of mentally ill.

Conflicts of interest

The authors have none to declare.

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