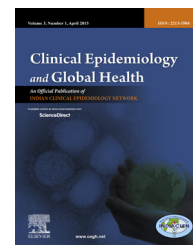


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Original Article

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

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