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Stigma and its correlates among caregivers of schizophrenia: A study from North India

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ABSTRACT

This study aimed to study stigma experienced by caregivers of patients with schizophrenia. One hundred caregivers of patients with schizophrenia were evaluated on Stigma scale for caregivers of people with mental illness (CPMI), Explanatory model interview catalogue stigma scale (EMIC), General health questionnaire-12 (GHQ), Self-report attitude towards medications questionnaire and Knowledge of mental illness scale (KMI). On CPMI the score was higher for affective component (2.3 ± 0.5) than for cognitive (1.9 ± 0.9) and behavioural (1.8 ± 0.6) components. More than half of caregivers 'agreeing' or 'strongly agreeing' on 20 out of 22 items of CPMI indicated high level of stigma. On EMIC the stigma score was 21.7 ± 6.3. Higher level of affiliate and/or associative stigma was associated with shorter duration of illness and treatment, shorter duration of being in the caregiver role, younger, female and non-earning caregivers, prescription of higher number of pills, caregivers who less often accompany the patient to the hospital and caregivers experienced more psychological morbidity. To conclude this study suggests that caregivers of patients with schizophrenia experience substantial stigma; hospital and community level programs and services are required to reduce and prevent the same.

1. Introduction

Caregivers' stigma in mental illness is categorised as associative or courtesy stigma, and affiliate stigma (Goffman, 1963; Mehta et al., 1988). Associative or courtesy stigma is understood as a process, in which a person is stigmatized by virtue of his or her association with another stigmatized individual (Goffman, 1963; Mehta et al., 1988). When people affiliated to stigmatized individual are personally affected by public stigma that prevails in the society, it is understood as affiliate stigma. As a consequence, these associates may feel unhappy and helpless about their affiliation with the stigmatized individual and perceive a negative influence on themselves (Mak and Cheung, 2008). Based on these cognitive and affective effects of affiliate stigma, caregivers may react behaviourally by concealing their status from others, withdrawing from social relations, or even alienating themselves from the targeted individuals to avoid association. This stigma may lead to unhappiness and helplessness, concealment of the illness, withdrawal from social relations, alienation or avoidance of the patient, and no or delayed treatment seeking (Helgason, 1990; Loebel et al., 1992; Mak and Cheung, 2008). Thus, affiliate stigma consists of three interlocking components: cognitions, affect and behavioural responses. Affiliates stigma differs from courtesy or associative stigma in that it includes self- stigma and corresponding psychological responses of the associates.

A survey from United States reported that 56% family members of mentally ill report experiencing stigma (Angermeyer et al., 2003). In another study 70% and 43% caregivers respectively believed that most people devalued those mentally ill, and their families (Struening et al., 2001). In an Australian study 30% carers reported reluctance to reveal their mental health carers status to people outside their close family and friends. The reason given was the experience of negative, hurtful and offensive attitudes from the media (49.0%), the general population (49.5%), as also the mental illness service providers. Health professionals had treated them/their ill relative 'differently' (43.9%), and 'as less competent' (43.8%), and they were told to lower their expectations (40.6%) (Mental Health Council of Australia, 2011). Characteristics of the family (sociodemography) and the mental illness (the stigmatizing mark), both are significantly related to stigma. Family members are more likely to conceal the illness if they do not live with the ill relative, the relative is female, and the relative has less severe positive symptoms. Mental illness of <6 months duration and family members with more education is associated with greater avoidance by others (Phelan et al., 1998). Studies also suggest a positive correlation between caregiver stigma and depression

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(Magana et al., 2007), suicidal thoughts (Ostman and Kjellin, 2002), thoughts that the patient would be better off dead (Ostman and Kjellin, 2002), caregiver burden (Magana et al., 2007) and delay in help seeking (Fernando, 2010).

Although there are many studies from India on various aspects of caregiving in schizophrenia (Chakrabarti, 2010; Kulhara et al., 2015), in general there is lack of information on stigma experience. Of the scanty Indian research in this area the earliest one (Thara and Srinivasan, 2000) reported 38% and 62% caregivers of patients with schizophrenia having 'high' or 'low' stigma experience respectively. Correlates of higher stigma were Hindu religion, female and younger patient as well as carer, shorter duration of illness, and when caregivers attributed the illness to 'no explanation', 'character or life style', 'substance abuse', 'problems in intimate interpersonal relationships' and 'faulty biological functioning' (Thara and Srinivasan, 2000). Another study with caregivers of schizophrenia reported concerns about the social impact of the illness on the affected person, problems in getting married or in existing marriage for the patients and their relatives, social devaluation, avoidance by others, concerns about disclosure, and feelings of shame and embarrassment about the relative's condition (Raguram et al., 2004). In another study, authors evaluated family members of women with schizophrenia and broken marriages and reported that these women feel disabled and stigmatised not only by their illness, but by the social attitudes to marital separation and divorce (Thara et al., 2000).

With this background, we conducted a research on the stigma in schizophrenia experienced by patients and their caregivers. As a part of that research the current paper focuses on the stigma experienced by the caregivers. Accordingly this study aimed to assess affiliate stigma and perceived stigma among the caregivers of the patients with schizophrenia. A secondary aim was to assess the relationship of the caregivers' stigma with their knowledge about illness, their attitude towards psychotropic medications and the clinical profile of the patient.

2. Methodology

This cross-sectional study was conducted at the psychiatry outpatient services of a tertiary care hospital in North India. The study approved by the Ethics Committee of the Institute and all the participants were recruited after obtaining written informed consent. The study sample was selected by purposive random sampling, i. e., initially a list of random numbers was generated and out of the 200 patients and caregivers who were fulfilling the selection criteria 100 were selected based on the predetermined random number. The study sample comprised of caregivers of 100 patients with schizophrenia diagnosed as per DSM IV [as assessed by MINI (Sheehan et al., 1998)]. The patients were to be: aged ≥ 18 years, suffering from schizophrenia for ≥ 2 years and in remission as per Andreasen et al. (2005). Patients with comorbid substance dependence, organic brain syndrome and mental retardation were excluded.

Caregivers were required to be living and intimately involved in the care of the patient for ≥ 1 year, i. e., looking after the daily needs, supervising the medications, bringing the patient to the hospital, staying with the patient during inpatient stay and maintaining liaison with the hospital staff. Such persons were also required to be spending ≥ 1 h/day in face-to-face contact with the patient, and be ≥ 18 years of age, free from any diagnosed physical or psychiatric morbidity (other than tobacco dependence) and able to read Hindi.

Caregivers completed the following self- administered instruments:

2.1. Stigma scale for caregivers of people with mental illness (CPMI) (Mak and Cheung, 2008)

CPMI measures caregivers' internalization of stigma (affiliate stigma) in terms of cognitive, affective and behavioural components. Participants' rate 22 scale items on a 4-point Likert scale from strongly disagree (1) to strongly agree (4). The mean scores for each component and for the whole scale are used to evaluate stigma; a higher score indicating a higher level of affiliate stigma. Cronbach's alpha of 0.95 reflects excellent internal consistency. To compare the severity of each component, we calculated the mean weighted score for each component, i. e., the mean score of each component was divided by the number of items included in the component. For this study, CPMI was translated to Hindi following the standard methodology and evaluated for psychometric properties in the form of cross-language equivalence and test-retest reliability and split half –reliability. These have been found to be satisfactory. The rating was based on the time period since the caregivers involvement/knowledge about one of their relatives having mental illness.

2.2. Explanatory model interview catalogue stigma scale [EMIC-Stigma scale (Weiss, 1997)]

EMIC-stigma scale assesses anticipated/perceived stigma, from the perspective of the stigmatised individual. It has 15 questions, with 4 answering options [Yes (3), Possibly (2), Uncertain (1), No (0)], with higher score indicating higher perceived stigma. As a generic scale it can be used for different health conditions. To evaluate the presence or absence of stigma the Yes, Possibly and Uncertain responses were re-categorised as 'Yes'. The rating was based on the time period since the caregivers involvement/knowledge about one of their relatives having mental illness.

2.3. General health questionnaire-12 (GHQ) (Goldberg, 1972; Gautam et al., 1987)

This 12-item version is a screening measure for psychological morbidity in primary care and community setting (Goldberg, 1972). This scale has been validated in Hindi with good psychometric properties (Gautam et al., 1987). A score of >2 was considered indicative of psychological morbidity (Cano et al., 2001).

2.4. Self-report attitude towards medications questionnaire (SRAQ) (Grover et al., 2014)

Based on Helbling et al.'s (2006), original tool to examine attitudes towards psychotropic medications in general, SRAQ was developed at our centre as a self-report questionnaire in Hindi language. Out of 18 items, 8 items focus on positive attitudes and 10 items on negative attitude. Many items evaluate culturally specific attitudes. The 3-point rating of the items yields 3 scores: for positive and negative attitudes and a total score. The scale has good internal consistency and split half reliability (Grover et al., 2014).

Additionally the caregivers were administered the following scales:

2.5. Knowledge of mental illness [KMI] scale (Kotze et al., 2008)

KMI assesses the knowledge about the diagnosis, symptoms, causes, medications and treatment. Its 5 items are rated on a three-point scale, higher scores indicate better knowledge about the illness.

Patients were evaluated on Positive and Negative Symptom Scale (Kay et al., 1987) and Global assessment of functioning scale (American Psychiatric Association, 1994).