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Perceived Stigma among Family Members of Persons Suffering from Mental Illness: A Narrative Exploration from West Bengal, India

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Abstract

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Keywords

stigma, mental illness, family members, social constructivism, narrative inquiry

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In this paper, we report the findings of a qualitative study that, aims to understand the family members' subjective experiences with perceived stigma of mental illness. The theoretical standpoint and the research method for the study employed are social constructivist theory and narrative inquiry respectively. We conducted semi-structured and in-depth interviews with family members and others accompanying patients to an outpatient unit of a psychiatric clinic. The professionals and the administrative staff at the clinic gave additional interviews. The constant comparative method was employed for the analysis of the narratives. The findings suggest the existence of perceived and direct stigma among family members. Family members shared their concerns relating to the disclosure of illness, its receptions, its interpretation by others, and the possible impact of the disclosure on the family. Professionals and staff at the clinic shared their perceptions regarding the manifestations of perceived stigma among families. In this study, we gathered an emic understanding of family stigma in the context of West Bengal, India. The findings are discussed in the context of current literature on stigma in India.

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Introduction

Mental illness, particularly severe mental illness, has a high level of stigma attached to it (Morgan, Burns, Fitzpatrick, Pinfold, & Priebe, 2007; World Health Organization [WHO], 2012). Interestingly, it is not limited to the patients; it extends to the family as well (Corrigan, Miller, & Watson, 2006; Lefley, 1989; Phelan, Bromet, & Link, 1998). Struening et al. (2001) reported that, 41-91% of the families surveyed in their study experienced the perceived stigma. Perceived stigma is also documented as an indicator of depressive symptoms among family members (Phelan et al. 1998). In a collectivist society like India (Markus & Kitayama, 1991), where family plays a significant role in health care, the experience of stigma of mental illness is only to be expected (e.g., Koschorke et al., 2017; Paul, 2016). Most Indian research on stigma, however, is focused on exploring its existence, while the subjective experiences of family members' stigma or family stigma are ignored. This paper aims to discuss subjective experiences of the stigma of mental illness amongst families in Indian society by reporting results from a qualitative study conducted in West Bengal.

Conceptualisation of Stigma

Society's response towards any kind of "undesired differentness" (Goffman, 1963, p. 5) is known as stigma. This can affect both physical as well as mental wellbeing, self-esteem, academic performance, social status, obtaining housing, job opportunity, and access to health care facilities (Major & O'Brien, 2005). Scholars have differentiated stigma into the following kinds: public or social stigma, self-stigma, and perceived stigma. Public stigma refers to the attitudes and reactions of society towards the stigmatised group (Rüsch, Angermeyer, & Corrigan, 2005). The internalisation of stigma (i.e., felt or self-stigma) may function through the individual who suffers with deviance and leads to the devaluation of oneself and a decreased sense of personal control and self-esteem. This induces anticipated rejection and the feeling of shame which results in withdrawal from the society or a non-help seeking attitude (Corrigan, Kerr, & Knudsen, 2005; Gray, 2002). Perceived stigma, which is different from self-stigma, denotes the awareness of existing negative stereotypes (Livingston & Boyd, 2010) among members of the stigmatized group(s). In the context of mental illness, Horwitz (1982) distinguishes between the "psychiatric models of stigmatization" and "sociological or labeling model" (cited in Littlewood, Jadhav, & Ryder, 2007, p. 172). According to the psychiatric model, the responses of society to the illness are based on popular conceptualization of the same. The labelling model proposes that illness is the product of cultural construction. It is the individual's response to a culturally-constructed perception of a "minor deviance" that can transform it into an illness or a disease category (Littlewood et al. 2007, p. 173).

Psychiatric Stigma in India

Stigmatization of mental illness has been extensively documented in the Indian context (e.g., Jadhav, Littlewood, Ryder, Chakraborty, & Jain, 2007; Loganathan & Murthy, 2011; Raguram, Weiss, Channabasavanna, & Devins, 1996; Thara & Srinivasan, 2000; Trani, Bakhshi, Kuhlberg, et al., 2015; Venkatesh, Andrews, Mayya, Singh, & Parsekar, 2015; Weiss, Jadhav, Raguram, Vounatsou, & Littlewood, 2001). Studies on psychiatric stigma in India and other Asian countries emphasised the contribution of culture in shaping expression of illness as per socially accepted idioms, such as somatic symptoms (e.g., Kirmayer, 1984; Kleinman, 1988; Nichter, 1981; Raguram et al., 1996). Therefore, the perceived stigma of mental illness which is also prevalent in Indian context majorly drives the expression of emotional distress (e.g., Böge et al., 2018; Koschorke et al., 2017; Zieger et al., 2016). Patients often had to cope with the labelling of the "illness" along with rejection by the partners, unemployment, and self or anticipatory stigma. Anticipatory stigma could lead to limited social involvement, concealment, and reduced help-seeking behaviour (Paul, 2016).

Recent studies report the existence of family stigma in the Indian context (e.g., Koschorke et al., 2017; Pawar, Peters, & Rathod, 2014) and also a high levels of perceived stigma among family caregivers in West Bengal (Mukherjee & Mukhopadhyay, 2019). Koschorke et al. (2017) identified two major aspects related to family stigma: (1) the families live in constant fear of disclosure of illness to the society; (2) they react negatively towards the patients because of their inability to meet the role expectations. This finding reflects two important aspects: first, the high degree of involvement of families in mental health care in India; and second, the depreciation in the family-patient relationship.

Indian Family and Mental Health Care

Care is a collective effort in Indian families irrespective of the types of illnesses. As a relativist society, Indian families, like families in other Asian societies, feel responsible to

provide care for their afflicted relatives. Indian family in general, is “a basic, cohesive, and integral unit of the larger social systems” (Sonawat, 2001, p. 177). Culture and society shape the family structure and the role-expectations (Chadda & Deb, 2013). Traditional Indian families are known as “joint families” where generally three generations reside together and are mostly patriarchal in nature¹ (Mullatti, 1995; Sonawat, 2001). The patriarchal society also promotes gender difference in families (Chekki, 1996; Sethi, 1989). Indian families have clear gender-role divisions, where a male member is expected to be a provider and protector and the female member is expected to take care of household activities.

In traditional joint families, there would be one significant family member (generally, an elder male member), who would take all important decisions related to the family (Mullatti, 1995). This decision-making also includes recognising symptoms as an illness, deciding upon treatments and doctors, and whether to continue with the treatment or not. Therefore, the explanatory models of illness (Kleinman, 1980; i.e., the beliefs and understanding related to an illness and its treatment) of the patriarch defines the course of illness and treatment of any illness. Illness, as Kleinman (1988) conceptualised, is a “polysemic or multivocal” (p. 8) concept that is not just the experience of the individual who is suffering from it; rather, it goes beyond the sick person’s experience and spreads over the wider socio-cultural context by incorporating the responses of family and society to the disease, their worldviews, and other treatment-related aspects. Therefore, the experience of illness in Indian families is shared. One of the benefits of belonging to a joint family is that in times of emotional distress, a person can share their worries with some family members and receive emotional support (Chadda & Deb, 2013). However, modern Indian families are becoming nuclear and smaller (Chadda & Deb, 2013). Although, most of these modern families are living separately, they also consult the elders in the extended family at times of decision-making or difficulties (Sethi, 1989). However, the changing family structure may also reduce possibility of sharing distress and perhaps act as a catalyst for increasing mental health problems in the Indian population.

Over 90% of the persons suffering from schizophrenia live with their families in India (Sharma, Murthy, Agarwal, & Wilkinson, 1998) and there are no welfare facilities or benefits available for them (Murthy, 2011). Owing to insufficient health care infrastructure, mental health professionals have encouraged families’ involvement in psychiatric care (Shankar & Rao, 2005). The active participation of families in psychiatric care in India has been well documented (Avasthi, 2010; Chakrabarti, 2011; Iyer, Mangala, Thara, & Malla, 2010; Nunley, 1998; Sethi, 1989; Thara, 2004). Studies report better trajectories of the effect and recovery of schizophrenic patients (e.g., Iyer et al., 2010; Sharma et al., 1998; Thara, 2004) and a strong association between good prognoses of schizophrenic patients and the attitudes of caregiving relatives (Verghese et al., 1990).

As Indian families have a high degree of involvement in care, they also have to endure the social stigma of mental illness; this might increase the burden of care and stress among families. Thus, it is imperative to study family members’ experiences of stigma in the Indian context to facilitate the development of culture-centric support programmes in future.

Thornicroft, Rose, Kassam, and Sartorius (2007) have observed that most research on the stigma of mental illness has given less importance to culture and contextual issues except for a few by Cheon and Chiao, 2012; Krupchanka et al., 2018; Lu, Chauhan, and Campbell, 2015; and Schulze and Angermeyer, 2003. A similar observation can also be made in the Indian context about a few remarkable studies (e.g., Jadhav et al., 2007; Koschorke et al., 2017; Raguram et al., 1996; Thara & Srinivasan, 2000; Weiss et al., 2001). Moreover, Thara and Srinivasan (2000) note that there is a dearth of in-depth studies addressing the families’ experiences of caring and responses towards stigma of mental illness in the Indian context. The

¹ There exist matriarchal families in certain regions of India (Mullatti, 1995).

current study address this relatively overlooked area with a social constructivist approach in the context of mental illness.

Relevance of Social Constructivist Approach and Narrative Inquiry

According to Guan and Liu (2014), stigma has been studied broadly under two different approaches: “individualism,” which emphasises stigma as an independent phenomenon, and “functionalism”, which considers stigma as a social process. However, these two broad approaches have failed to provide a complete picture of stigma (Guan & Liu, 2014). To address this issue, the current research highlights the importance of both socio-cultural and individual aspects of stigma, and is also highlights the interaction between the stigmatizer and the stigmatised (Guan & Liu, 2014) from the theoretical position of social constructivism.

The social constructivist approach assumes that reality is created through the interaction between the individual’s cognitive functions and the existing social, political, psychological and cultural contexts (Sparkes & Smith, 2008). The emergence of social constructivism in social psychology emphasised the importance of socio-cultural contexts and human interaction in interpreting and defining social phenomena and questioned the traditional positivist paradigm (Guba, 1990). Moreover, Goffman (1963) considered stigma as a socially constructed phenomenon that represents “a special kind of relationship between attributes and stereotype” (p. 4). Conceptualizing stigma as an interaction between family members’ cognition and available discourses related to stigma would enhance the understanding of the phenomenon at an intersubjective level. Thus, the present study conceptualises the construct of stigma as the product of family members’ perception and meaning-making (cognitive involvement in meaning making) about their treatment in the society based on the existing discourses related to stigma (socio-cultural context) of mental illness. Exploring the subjective aspects of stigmatization could give us an in-depth understanding of the social stigma of mental illness in the Indian context.

Methods

During the pilot study, it appeared that the families had a tendency of depicting their experiences in the form of narratives. Accordingly, we decided to employ narrative inquiry as the research method. Scholars in narrative research suggest that individuals construct their lives through narratives; narratives are contextual and are shaped through the interaction between the social, cultural and personal worlds of individuals (Sparkes & Smith, 2008). Narrative inquiry, as informed by social constructivism, is of the view that “narratives and people’s life stories are psychosocial or intersubjectively created” (Sparkes & Smith, 2008, p. 297). Thus, the illness narratives of family members are shaped by meaning-making processes, beliefs and explanatory models, and social discourses (through interactions with patients, professionals, and others) that are embedded in the immediate cultural context.

The Study

The study was conducted during the years 2010-2012 at an outpatient unit of a psychiatric clinic, run by a non-government organization (NGO) in Kolkata, West Bengal, India. The clinic had an annual turnout of 10,000 patients including the dropouts. Patients from rural as well as urban areas visit the clinic for treatment. The study followed three major lines of inquiry: (1) What are the experiences of family members regarding caregiving? (2) How do the caregivers understand (explanatory models) mental illness and its treatment? (3) What are

the experiences of family members related to the stigma of mental illness? This paper highlights the findings of the third line of inquiry.

The main study comprised of five interconnected phases: (1) Phase I: A pilot study to develop a working plan for the main study; (2) Phase II: Semi-structured interviews with families related to explanatory models of illness and unstructured in-depth interviews with families related to their experiences of caring; (3) Phase III: Semi-structured interviews with mental health professionals and the administrative staff at the clinic, and the first follow-up interviews with families interviewed during Phase I; (4) Phase IV: The second follow-up interviews with families interviewed during phase I; and (5) Phase V: Unstructured interviews with a few folk healers (not included in this paper).

The participants. During the pilot phase, we decided to incorporate the professionals' interviews along with the families to get a holistic understanding of the care-giving experiences. The families were reached through purposeful sampling, guided by the research questions (Miles & Huberman, 1984) and maximum variation strategy (Patton, 2002). The first author conducted the field work. The psychiatrists on duty approached the participants, shared the study information and purpose, and introduced the researcher. Following this, the researcher approached the family members who had agreed to participate in the study and explained the research purpose and objectives in detail. Most patients came to the clinic with family members. In some cases, patients also came with friends, neighbours, and other relatives and they were also interviewed along with family members. The variations noted were the types of mental illness, gender, kinship between the patients and participants, duration of caregiving, family type, and domicile.

The interviews. The study began after acquiring the approval of the Departmental Doctoral Committee and of the Ethics Board of the clinic². The first author explained the purpose of the study to the participants and obtained verbal consents for their interviews.³ 85 participants (family members and other accompanying persons) from 68 families participated in the study.⁴ 48 participants (from 38 families) took part in the semi-structured interviews (20-25 minutes), and 37 (30 families) participants participated in the in-depth interviews (60-90 minutes). One participant was taking care of two of her relatives. Demographic characteristics of the patients, family members and others are presented in Table 1 and Table 2. Almost all the interviews were recorded and saved in MP3 files.

Eight professionals (psychiatrists, clinical psychologists, and nurses), two attendants, and six administrative staff at the clinic took part in the semi-structured interviews. All four psychiatrists were male and residents of urban areas. The two clinical psychologists were female and unmarried; they had been practicing psychotherapy for the last fifteen years and eight years respectively and lived in the urban area of Kolkata. Both the psychologists were registered with the Rehabilitation Council of India (RCI). There were two female nurses who worked in shifts. The two attendants interviewed were male and they took care of the inpatient unit of the clinic. Among the staff, four female members had the responsibility of managing the reception area. The other two staff were responsible for other administrative jobs and worked from 9:00 am to 8:00 pm.

² At the time of data collection there was no ethics committee at the Institute for human subjects. Therefore, we followed the standard practice which include: getting approval from the institute doctoral committee; and acquiring the letter of permission and certificate of data collection (at the end) from the clinic's ethics board.

³ Due to high level of stigma attached to mental illness, the professionals at the clinic advised us to avoid taking informed consent on paper. According to them this might have led to a great number of refusals for interview from families. During data collection it was observed that many families were uncomfortable for voice recording even after going through the official documents related to the study. Few families also refused to give recorded interviews.

⁴ Two interviews also collected from participants who recognized themselves as "self-carer" in the main study. Those interviews were not included in this paper.

Table 1
Demographic characteristics of the patients

Demographic Characteristics		Numbers (N=69)
Age (Years)	<= 20	14
	21-40	39
	41-60	10
	> 60	6
Sex	Female	33
	Male	36
Marital Status	Married	26
	Widower/Widowed	5
	Unmarried	38
Duration of Illness (Years)	< 1	6
	01-05	29
	05-20	22
	>=20	11
	Unknown	1
	Stable (Follow-up visit) and Improving stage	33
Illness types	Severe mental illnesses (Schizophrenia and Mood disorders)	42
	Common mental illnesses	11
	Co-morbidity	16
Occupations	Students	18
	Employed (Government and private sector, and business)	24
	Homemakers	15
	Unemployed	12

Table 2
Demographic characteristics of the family members and other accompanying persons

Demographic Characteristics		Numbers (N=85)
Age (Years)	<= 20	1
	21-40	28
	41-60	45
	>=60	11
Sex	Female	46
	Male	39
Marital status	Married	71
	Separated/ Widowed	8
	Unmarried	6
Kinship with the patients	Spouses	23
	Parents	40
	Children	4
	Siblings	6
	Other relatives (Uncle, Aunt, Cousin, Nephew, Niece, Sister-in law)	10
	Friends and neighbours	2

Duration of care (in Years)	<1	14
	1-10	48
	10-20	9
	>=20	8
Occupations	Students	1
	Homemakers	28
	Employed (Government, private jobs, business, and other jobs)	43
	Retired (Pension holders)	10
	Unemployed	3

Based on the pilot study and review of literature, we prepared interview guides for the interviews. All the interviews began with the following question: “*Can you please share your story?*” or a statement like “*Please share what happened with you.*” The interview guides were flexible and were modified every time. Some examples of the questions are provided in Table 3. The demographic details of the participants were collected using a self-developed demographic data sheet. All except two interviews (one in Hindi and the other one in English), were conducted in Bengali. Along with interviews, the first author maintained a field journal to record field observations, and memos to support the analytic process. The entire data collection was self-reflexive and iterative.

Table 3

Some examples of questions asked to the family members during interviews

- 1) Do you often share your relative’s problem with others (neighbours, extended family members, friends etc.)?
- 2) How much information you can share with others?
- 3) Did you ever feel any hesitation in sharing this information?
- 4) If yes, then can you explain what kind of hesitation you feel and why?
- 5) How do other people react, when they come to know about your relative’s condition?
- 6) Do you feel there will be any kind of discrimination if others know about your relative’s illness?
- 7) What kind of impact the reaction of others might have on your family?
- 8) What is your own feeling about your relative’s condition?
- 9) Would you like to share about any situation where you have experienced discriminations because of your relative’s mental illness, either directly or indirectly?
- 10) How being aware of the stigma associated with mental illness has affected your attitude or behaviour?
- 11) What could be the possible impact of this awareness in your social life?

Locating the researchers within the research context. The first author interviewed families and professionals at the clinic and interacted with them. Being a Bengali and being familiar with the culture was an additional help for building rapport and for gathering the subjective experiences of the caregivers. To maintain self-reflexivity in the research process, the first author maintained a reflexive journal throughout the research where she acknowledged her beliefs about mental illness and its treatment, her understanding of stigma, her stigma of mental illness, and how she conceptualized care. This helped her to understand various other perspectives shared by the families. The first author also acknowledged the challenges she faced in maintaining a non-judgmental position during data collection processes. Once, during the data collection phase (phase II), while waiting for an interview at the reception area, a

family member thought her to be a patient and asked about her illness. The first author was initially shocked to be addressed as “a patient” but also felt embarrassed after realising her stigma of mental illness. She depicted that incident as a wake-up call. The second author who was from a neighbouring state of West Bengal and shared almost similar cultural values and understandings. She was involved during the planning and analysis phase.

Data saturation. The concept of saturation is defined in the grounded theory premise as the non-emergence of new codes or theoretical understanding from new interviews (Saunders et al., 2018). Outside the grounded theory research, saturation is often understood as data saturation, that is, repetition of similar concepts in successive interviews (Saunders et al., 2018). In this study, data saturation was reached after the first author observed repetitive contents in the last six interviews.

Data analysis. Interviews were transcribed and then translated into English. For the analysis of narratives, the Constant Comparative Method (CCM; Glaser, 1965; Lincoln & Guba, 1985) was employed. Although CCM is generally used in the premise of grounded theory methodology, it can be used in other contexts as an analytical technique to handle larger data and to retain emic knowledge gathered from the field (Fram, 2013; Lincoln & Guba, 1985).⁵ The authors here intended to use CCM to establish “analytical distinction” (Charmaz, 2014 p. 132) and to maintain the emic aspect of the data after analysis, not to generate a field-based grounded theory related to caregiving experience.⁶

Initial and focused coding techniques were employed to identify and develop codes and categories. Initial coding was done line-by-line and segment-by-segment to extract “theoretical possibilities” from the narratives and to get a direction towards the “core conceptual categories” (Charmaz, 2014, p. 116). It began with reading and re-reading the transcript of the first interview (also, re-listening to the interview) and identifying and highlighting potential lines and segments related to caregiving experiences, followed by comparing these lines and segments. The second narratives were processed similarly and compared with the first narratives. After the completion of the eighth interview, the authors developed an analysis key and employed it for rest of the analysis. However, the key was flexible, and if new codes emerged during the process, they were considered. Supportive data utilised during analysis included field notes and memos written during data collection. Converging and comparing initial codes led to focused coding, and eventually, led to the emergence of core conceptual categories that reflected the research objectives. Examples of initial and focused codes are presented in Table 4.

Research rigour. To maintain research rigour, the authors followed certain steps at different phases of the study: during the pilot phase, participants’ (families and professionals) responses were considered and incorporated in the development of the interview guides. At the data collection phase, the interview guides were modified after each interview. Data triangulation was used with regards to the multiple data sources (Whitley, 2011). The entire

⁵ At the time of deciding about the analytical methods, the first author was in e-mail correspondence with Prof. Kathy Charmaz and discussed the possibilities of applying CCM in Narrative Inquiry. As per one of such email by Prof. Charmaz, she wrote: “*I do not have problems with researchers drawing from more than one approach. Those who prefer distinct boundaries do have trouble with it.*” (Personal communication, dated 27th January, 2014).

⁶ In the main study, we have taken a dual analyses approach based on Polkinghorne’s (1995) division: analysis of narratives and narrative analysis. Previously, McCance, McKenna, and Boore (2001) have applied the combination of these aforementioned two analyses techniques in their research to get a holistic picture and in-depth understanding of caring. The analysis of narratives is founded on paradigmatic reasoning. Here, the data is in the form of stories, and the analysis is conducted with multiple cases. The content of the narrative is important in this type of analysis. The focus is to identify or search for common patterns and themes across cases. For analysis of narrative, we used CCM as the analytical method. We also developed five case studies with narrative analysis approach.

research process was self-reflexive. The first author maintained a reflexive journal along with a filed journal to understand personal biases and beliefs regarding mental illness and its care. Respondent validation was conducted after the completion of each phase and during the follow-up interviews. Data saturation, also considered as one of the important parameters for qualitative rigour (Morse, 2015), was reached after observing repetitive contents in the last six interviews. After data collection, a Social Science professional audited and checked the authenticity of the interviews. A Bengali-speaking professional, who was also trained in English checked the translations of the interviews. Both the authors participated jointly in the analysis process; maintained a reflexive approach during coding; and were careful to preserve the subjectivity of the narratives as far as possible. Besides, as suggested by Riessman (1993), to aid the trustworthiness of the research, a detailed description of the study process was maintained as well.

Table 4

Major categories, subcategories and codes

Categories (Number of Codes)	Subcategories (Number of Codes)
Major category 1: Perceived stigma: Family members' perceptions and concerns (251)	<i>"How others would react?" (107)</i> <i>"They don't understand it." (51)</i> <i>"They would treat us differently." (62)</i> <i>"If we disclose about the illness, no one will marry him." (31)</i>
Major category 2: Direct experience of stigma (17)	
Major category 3: Manifestations of perceived stigma: Professionals' accounts (81)	<i>Avoiding psychiatric treatments and preferring counselling (19)</i> <i>Concealment of identity and illness (33)</i> <i>Arranging marriage of the patients (29)</i>

The Findings

A total number of 268 incidences coded (initial coding) from the transcribed narratives related to the third line of inquiry (i.e., "What are the experience of family members related to stigma of mental illness?"). Further analysis of these 268 codes revealed the presence of both perceived (251 codes) and direct stigma (17 codes) among family members. Initial coding of the professionals' accounts revealed 81 incidences related to their perception about family stigma and what families generally do to avoid the said stigma. The field notes and memos written during the data collection phases were also used during initial coding to get a better understanding of the codes. After focused coding, three major categories were identified:

- I. Major category 1: Family members' perceptions and concerns (Perceived stigma)
- II. Major category 2: Direct experience of stigma
- III. Major category 3: Manifestations of perceived stigma: Professionals' accounts

The categories and subcategories are presented in Table 4. A separate section is also added as a "general observation" at the end of the analysis to incorporate the first author's field

experiences. The findings of the first and second lines of inquiry discuss the caregiving experiences, and psychiatric pluralism, and explanatory models among family members in the context of West Bengal. The findings from the second lines of inquiry have been published as a separate paper (Banerjee & Dixit, 2017).

Family members' perceptions and concerns. Most participants expressed their preconceived ideas of societal reaction when asked about their relatives' mental illness. They also expressed their concerns regarding the consequence of the disclosure of illness for them and their families, which also reflects their perceived stigma of mental illness. Family members' perceived stigma has been discussed under four subcategories that have emerged during the analysis.

"How others would react?" Most participants were concerned about how others (extended family members, the neighbours, and friends) would react to the illness in the family. They were concerned about what would others say behind their backs. These concerns led them to conceal details of the illness and the treatment from others. One participant said that he lied to his neighbours about his son's admission to the inpatient unit of the clinic to avoid being judged. According to him, once the neighbours discovered the truth, they would react negatively towards the patient and the family. Another participant shared her position of hiding her husband's illness with the following words:

It (mental illness) must be concealed, because, it feels bad. Everyone would think that my husband is mad ... they would directly say her husband is mad. That's why I do not share these things with others...I try not to reveal it...till date I didn't.

Some participants also shared their concerns about how "others" would interpret the illness as hereditary. They felt that the entire family would be judged and labelled as "mad." In contrast to the majority, a few participants shared that they do not think mental illness should be hidden from others. For example, a participant said - *"I don't think it (mental illness) should be hidden from others. It's just like other illness, where we take medicine and get cured. With proper treatment, mental illness can also get cured."* These participants have been dealing with the mental illness for a long time and some of them have been exposed to mental illness in family.

"They don't understand it (mental illness) properly." Most participants believed that "the others" cannot understand the illness and as a result might perceive the patient as threatening and harmful. A participant expressed that-

...They don't know about it, they don't understand it...I know why my son is behaving like this, they don't have that kind of understanding that we have about mental illness. If I tell them about it (mental illness), they might think my son is aggressive or he could harm them etc.

Another participant justified her position of nondisclosure to her extended family by highlighting their conservative beliefs:

My in-laws don't know anything. We don't tell them. You know ... they are not that open minded about it... they are very traditional. They might taunt me and my family for this. When they ask about my son, I tell them he is busy preparing for exam, etc.

Most participants shared the notion that others do not have proper knowledge about mental illnesses, its types, and its treatment options. However, most of them also shared that they didn't have much idea about mental illness themselves until their relatives were diagnosed with the same. A few of them had some prior knowledge about mental illness based on their experience.

Some participants also shared their concerns about visiting mental health clinics and consulting with psychiatrists. They expressed their fear of someone (such as neighbours) finding out about the visit and how that would impact their social lives. One participant shared that:

No one knows I am visiting this place. I told them I am going to Kolkata for some work. But if someone sees me here or coming out of this place, then he will spread the news to our neighbourhood and everyone would think I am mad.

“They would treat us differently.” Family members in this study also shared their concerns about how “others” would treat them once they find out about the illness. Many of them were anxious that the patient as well as the family would be discriminated against and excluded from social activity, or they might face social discrimination. One participant shared: *“If her friends got to know about her illness, they might boycott her or tease her.”* On the other hand, a participant shared that once others knew about the illness of the patient, they might become over sympathetic. In addition, another participant shared how she feared her son might lose his job if his colleagues might find out about his illness. She mentioned-

This is the second company for him (her son)... At the time of his first job, he was diagnosed with the illness and he had to discontinue with his job because he was hospitalised. This time if his colleagues get to know about his condition then the admin (office administration) will also know and he might lose this job.

The anxiety about others finding out and about how they would judge the family also impacts the social lives of some participants. A few participants shared that they avoided social gatherings to avoid being asked about their relative's whereabouts. A participant expressed how she and her husband even stopped inviting friends and distant relatives home to avoid embarrassing situations. The participant said:

We don't know how the situation would be at home. Most of the time he acts aggressively...he shouts, he breaks things... its always embarrassing for us. That is why we avoid calling our friends and relatives to our home. It's always unpredictable.

“If we disclose about the illness, no one will marry him.” Most participants were concerned not only about the marriage prospects of the patients, but also with the prospects of others in the family. They were concerned about the family's reputation. There were cases where the family concealed the illness at the time of negotiation and marriage. In the following excerpts, a participant, who got her son (the patient) married by hiding the illness from the bride's family, shared:

The researcher: *Did you tell the other family (bride's family) about the illness?*
The mother: No, it was not that important. He was doing well, he has a government job. These days that is all - a government job, a well to do family.

My husband was an WBCS officer. We have some reputation. We did not tell. Otherwise (a long pause) ... I mean, these kinds of thing we don't tell others.

The researcher: *Can you further explain why we don't tell about the illness to others?*

The mother: We don't tell. No one would understand it. They would think it is heredity and if you tell them, they would say no to the marriage.

There were many participants who asked the first author whether anyone would marry their sons or daughters. They also expressed their concerns about how their disclosures of the illness could impact the marriage prospects of others in the family. In one such extreme case, the first author received a marriage proposal from the mother of a patient during the interview: *"Since you have psychology background and working in this area, and you understand the illness, you can think of marrying my son."*

Direct experience of stigma. Some participants narrated direct experiences of stigma within the family itself. A woman who stayed at her in-laws' place while also taking care of her mother who was suffering from a severe mental illness, narrated her experiences. According to her, although, the onset of the symptoms of mental illness in her mother occurred long after her marriage, her in-laws had accused her family of concealing it at the time of marriage.

Ma (mother) is sick. I mean, she is a mental patient. So, people talk about it at neighbourhood and at my in-law's place. But they (in-laws) assume that *ma* had this problem from the beginning and its genetic, and we concealed it from them at the time of marriage. Often, I have to listen to such accusations. I feel bad. Listening to those allegations. After all, she is my mother!

Another participant who lived with her in-laws and was taking care of her father who lived alone narrated a similar experience. She said that sometimes when she would get upset and lose her temper, her husband would taunt her by saying *"you will also have this (mental illness) like your father."* In another case, a participant shared how his son is not getting a job at his village because everyone knew about his mental illness.

Manifestations of perceived stigma (Professionals' accounts). Analysis of the professionals' interviews reflected their perception about mental illness stigma amongst families. They observed certain trends amongst families who visit the clinic such as a general negative attitude towards psychiatric treatments, especially psychiatric medicines and being referred to a psychiatrist; preferring counselling (over psychiatric treatment); concealment of identity and illness; and arranging marriage of the psychiatric patients.

Avoiding psychiatric treatments and preferring counselling. The professionals shared that there is a general avoidance of psychiatric treatment in families. A reception staff, who manages the appointments shared that often families asked for a counsellor by claiming that the problem was not mental health related and that they just needed to see a counsellor. The staff narrated an incident about a man seeking an appointment with a psychologist for his brother. His sister was undergoing psychiatric treatment at the same clinic.

He was saying that *"I want to make an appointment for a psychologist. He needs counselling."* I asked him *"Have you consulted a doctor?"* *"No, I consulted the doctor for my sister, but I want to arrange a counselling session for my brother."* Then I asked him *"What's the problem?"* He said ... *"Actually, my brother is talking like an illiterate these days."* Then, I suggested him to see the

doctor first. I asked him “*Did any doctor suggested you to go for counselling?*” Then he replied, “*No no my brother is not mad.*”

The staff believes that ignorance, lack of clarity about mental illness, and social stigma have been instrumental in creating a preference for counselling. The staff believes that the psychiatrist is the one who should decide the therapy. Other professionals at the clinic related similar incidents where the families of patients asked for a neurologist rather than a psychiatrist. According to them, most families or patients tried to book an appointment with a neurologist (the clinic did not have a neurologist) by claiming that the problem was neurological. These professionals felt that consulting a neurologist or a psychologist evokes less stigma than consulting a psychiatrist.

Concealment of identity and illness. The professionals at the clinic observed that families often hid the illness from others, and also provided wrong information about their identity, personal details and contact addresses. Consequently, the staff were unable to follow up with them in case of prolonged absences or to share important information such as changes in appointment, psychometric reports etc. Similarly, the first author faced difficulty in accessing families for follow-up interviews and respondent validation because most families had provided false contact information. A psychiatrist at the clinic observed that the tendency of non-disclosure was more common in urban areas as compared to rural areas. He said-

To say it *honestly* ...to tell you about *rural population* ...I would say that ...*this kind of stigma is much less than urban population. Urban population do it more. The rural population would come to the doctor ... there it is more acceptable.* Suppose, there are many patients in a village who got cured by the doctor for their illness (mental illness) ... from that place some people suggest the patient’s family to talk to the other patient’s family and from there they get reference of the doctor. That means that the patient and family did not keep the illness from others. That means they have talked about it to other people. In urban places the hiding is more, but in villages people know each other and sharing is more. Here (in city) after the *flats* (apartments) came up; no one knows about others or *does not care.*

According to one staff, there was a case where the wife of a patient had registered her own name as that of the patient in order to hide the husband’s identity. The wife regularly visited the clinic for medication and follow-ups instead of her husband who visited the psychiatrist only occasionally. Since such instances were common, the clinic accepted them; the acceptance of such behaviour ensured at the very least that the patient received the required treatment. Diametrically opposite to this incident is another, where a participant registered himself as patient to get his wife’s treatment done. In this case, the patient did not have any insight about her illness and believed that her husband was the one who was suffering from some mental illness⁷. The professionals and the staff at the clinic attributed the tendency of concealment of illness and identity by families to the desire to avoid existing psychiatric stigma. One such professional expressed that:

Often, these families hide their address and identity to avoid stigma. It is very common. It is also common among students...That is why it becomes very

⁷ The patient was under impression that her husband is suffering from some mental illness and she was taking care of him. She was diagnosed with paranoid schizophrenia and has multiple manic episodes. The doctors at the clinic suggested that her husband get himself registered as a patient so that the patient can come to the clinic for check-ups. She was given psychiatric medicines in the name of vitamin tablets and stress relief.

difficult for us to do a follow up. Recently, to avoid such situation we have made the voter I-card (Government Identity card) mandatory at the time of registration. But still ...many of them are not taking it seriously.

Arranging Marriage of the patients. Hiding the illness from the spouse's family in order to be married was a common practice as observed by the professionals and staff at the clinic. Although the psychiatrists always encouraged the families to disclose everything to the prospective partners and families, families often hid the fact and arranged fixed the marriages when the patients were in a relatively stable mental state. A psychiatrist narrated how some families managed to hide the illness and handle the relapse of symptoms:

In most cases what happens that they (the families) might ask once or twice whether the marriage is possible or not. We say, there is no problem in marriage...after all marriage is a personal choice and because someone is suffering from schizophrenia that's why she could not get married, or "she" might have problem in pregnancy or "he" could not become a father ...it's nothing like that. There is no problem in marriage. But the medication should be continued and it would be the best thing to inform the other family before marriage. But, what we hear, often, the families hide the illness from the other family and when the illness recurs, the family takes the patient to the psychiatrist by saying it is the onset of the problem and they come and request us not to mention about the previous consultations to the other family. Sometimes they consult a new doctor who does not know them.

General observations from the field (researcher's experience). During data collection phases, the first author encountered certain experiences that may be discussed in the context of psychiatric stigma amongst families. Most families were reluctant to give recorded interviews; however, they agreed to do so after considering the official documents. In some cases, the families were not convinced and refused to give recorded interviews. Once, a participant got suspicious about hidden cameras (though there was no camera inside the room) and left the interview midway.

Participants, mostly the parents of male patients, repeatedly try to establish that, despite the mental illness their son was otherwise "normal" and attempt to present them as "*a good boy*" (*bhalo chele*). During initial readings of the interviews, it was observed that, the statements, such as "*he is otherwise normal,*" "*he is a good human being,*" "*he is a good boy,*" and "*these are just some symptoms, but he is normal*" appeared several times in the narratives and contained a sense of assurance. In doing so, these parents perhaps wanted to convey that their sons conformed to the parameters of "normality" and "ideal behaviour" in Bengali culture. It is to be noted that the narratives of parents with a female child demonstrated a contrasting attitude. All of them were critical about the illness symptoms and did not try to highlight the positive dispositions of their daughters.

Moreover, most participants who were the parents of patients, claimed that the patients had inherited the illness from their (the participant's) spouse. In the process of emphasising the hereditary factor, these participants stressed that their own families were free of mental illness. By highlighting the cause of illness as the genetic transmission from the spouse's family, these participants perhaps tried to avoid being associated with the illness and hence, tried to protect their own family from the stigma.

Finally, it was also observed that, some families who were exposed to their neighbours due to symptom manifestations (e.g., manic episodes) shared less concerns about disclosure of mental illness. These families mostly dealt with direct stigma as well as with the burden of

caregiving. These families shared that since everyone in the locality knew about the illness, they had no need to hide or lie about their afflicted relatives. Some of these families also shared how they received help from their neighbours while handling difficult situations at times. As mentioned earlier, most patients were accompanied by their family member/s and others (neighbours, friends, extended family members) to the clinic. These accompanying persons came to help the family manage the patients during travel, locate the clinic, and in some cases, they even took the decision for the family in choosing the clinic, the professionals, and the mode of treatment. (Banerjee & Dixit, 2017).

Discussion

The narrative inquiry depicted in this paper explored the subjective experiences of stigma amongst family members in the context of psychiatric treatment in West Bengal. To get a holistic understanding of experiences of family stigma, the authors attempted to incorporate different stakeholders' perspectives in a single study. In addition, the researchers' observations during field work have been incorporated within the main analysis. Existence of perceived and direct stigmas related to mental illness were identified within narratives. The professionals' accounts supported the findings that emerged from the family members' narratives. They shared their perspectives about how the perception of stigma is manifested within families.

The findings of perceived stigma in family members' narratives highlight their worries and concerns related to the disclosure of the illness, the possible consequences of the disclosure, and the reception of the information by others (neighbours, friends, extended families, etc.). These concerns led them to consciously hide the illness as well as the details of treatment from others. Their justifications for their actions reflect their concerns about protecting family reputation as well as protecting their own selves. The findings described their worries regarding the marriage prospects of the patients as well as other members in the family. Studies previously conducted in other parts of India in similar psychiatric contexts (e.g., Koschorke et al., 2017; Loganathan & Murthy, 2011; Paul, 2016; Weiss et al., 2001) also reported concerns related to the disclosure of illness and its treatment, protecting family reputation, and worries about marriage prospects of the patients and family. Perceived stigma related to mental illness has been previously reported in different contexts such as in Ethiopia (Shibre et al., 2001), in Uganda (Muhwezi, Okello, Neema, & Musisi, 2008), in Namibia (Bartholomew, 2017), in New York (Phelan et al., 1998), and in Canada (Ryder, Bean, & Dion, 2000).

Being protective of the family reputation or portraying the afflicted son as "a good boy" could be rooted in the concept of self. The Indian self is "*di-vidual*" or dualistic in nature (Roland, 1988; Sinha et al., 2010), (i.e., it has both relational and individualistic sides). The care-giving roles and the protectiveness stemming from belongingness and attachment reflect the participants' relational selves. Caring for others also counted as *dharma* (moral responsibility). By fulfilling their *dharma*, they gain *punya* (reward of or return for one's piety or virtue) for themselves, which is indicative of their individualistic self. Besides, the sense of responsibility towards their kin is also embedded in the participants' efforts to meet the societal role expectations. Kakar (1978) has discussed that in the Indian context people generally conform to the role expectations of society. In addition, the contrasting attitudes of parents depicting mental illness in male and female patients reflect the patriarchal structure of Indian families (Johnson & Johnson, 2001) that leads to the apparent gender discrimination in upbringing, expectations, education, and other social aspects (Goswami, 2013).

The participants' tendency to portray mental illness as a neurological problem could be rooted in the socially accepted illness expression (i.e., somatization). Loganathan and Murthy (2011) reported that psychiatric patients often masked the psychiatric symptoms with somatic

symptoms as they are more acceptable in Indian society. This is also supported by a comparative study conducted in India and London by Weiss et al. (2001). Moreover, Koschorke et al. (2017) observed that people often blame families for the illness (for negligence, giving birth to etc.) and the illness affects the family reputation. Therefore, perhaps to protect family reputation, the participants even went to the extent of suggesting that the illness was actually transmitted through marriage. Moreover, to avoid social exclusion, the families often tried to conceal the diagnosis of mental illness and its treatment from others. A similar observation was reported by Paul (2016) and Koschorke et al. (2017) in India. As noted earlier, the accounts of the staff at the clinic do suggest that families often provided false identities at the clinic to avoid public disclosure and therefore, to avoid stigma. This tendency is also observed amongst patients and families in Ethiopia by Shibre et al. (2001).

This tendency to conceal identity and illness among the urban population suggests the existence of perceived stigma and is also corroborated by previous studies that have reported less stigmatic attitudes towards persons with mental illness in rural areas (e.g., Cooper & Sartorius, 1977; Neki, 1966; Srinivasa & Trivedi, 1982; Ta et al., 2016; Warner, 2004; Waxler-Morrison, 1992). On the other hand, the present observation is a contradiction to the findings of a large-scale study by Jadhav et al. (2007) that reported that psychiatric stigma is found to be more in rural areas than in urban areas. One might suggest that the lesser representation of participants from the rural background in the present study could be one of the reasons that led to such an observation. At the same time, the preference for counselling in urban areas also reflects the negative attitude towards mental illness and psychiatrists. A similar observation is made by Zieger et al. (2017) in a survey conducted in five metropolitan cities in India (Chennai, Hyderabad, Kolkata, Lucknow, and Mumbai). It may be argued that perceived stigma may also act as a motivating factor for the families to hide the illness from society and wait for the cure. By doing this they can avoid being labelled or stigmatised by the society (Raguram et al., 2004).

Marriage is considered as one of the major milestones towards leading a normal life for an individual (Cook, Cohler, Pickett, & Beeler, 1997) and a person fulfilling these criteria and adhering to marital responsibilities is seen as fulfilling his or her duties and therefore, on the path of *dharma*. Koschorke et al. (2014, 2017) discussed how, in the Indian context, a patient's reduced ability to meet role expectations in terms of marriage and occupation impacted the family, and thereafter induced social stigma. However, in the present study, families were found to be worried about the patient's prospect of marriage and job and therefore, tried to hide it from others. The marriage prospect of a psychiatric patient could be hampered by the disclosure of the mental illness and it could have a detrimental impact on the marriages of the other family members (Koschorke et al., 2017; Thara & Srinivasan, 1997). Additionally, Loganathan and Murthy (2011) reported that families often hide mental illness from one's own family to avoid being rejected by potential marriage prospects, as marriages within the family is a common practice in certain regions of India.

The social constructivist theoretical lens and multiple data sources of the present study provided an emic understanding about the psychiatric stigma of mental illness and its manifestations in the context of West Bengal. Perceived stigma was manifested through the interaction between the individual's perception about possible consequences of the disclosure of the illness and the available discourses in the socio-cultural context. Families with relatives suffering from mental illness were well aware of the negative and stereotypical discourses and practices in the society. Awareness of such discourses perhaps, influences their perception and explanation of mental illness, shapes their preference for counsellors over psychiatrists, motivates them to maintain "normalcy" through marriage, and doing whatever is possible to cure their relatives. The in-depth understanding of experiences of family stigma provides insight into the culture of Indian family values and protectiveness.

It needs to be stated that the present study has some limitations as well. It was conducted in only one psychiatric clinic and did not include other healing centres such as Ayurvedic, homeopathic or folk healing. Such an inclusion would have broadened the understanding of the study. Nevertheless, the present study contributes to mental illness stigma research by exploring the subjective experience of family stigma in the psychiatric context in India. Furthermore, previous studies were conducted to understand either the patients' or family members' perspectives. By incorporating multiple stakeholders in a single study, the authors gathered an in-depth and holistic understanding of perceptions of stigma in the Indian context.

The in-depth knowledge generated from this study can be potentially used to develop a community level programs for the affected families to equip them to deal with mental illness stigma as well as an anti-stigma program specific to West Bengal. The findings also indicate a need for mental health education programs that may be useful for reducing psychiatric stigma in the local context. Moreover, the findings can be used for development of policies for families dealing with mental illness in India. Furthermore, the understanding gathered from this study can also be used as a foundation for replicating similar study and programs in other states in India, and eventually in other Asian countries. As WHO (2001) prioritised the stigma reduction program to improve mental health, more culture-centric research related to stigma is necessary. Future researchers can focus on the gendered aspect of psychiatric stigma and marriages of psychiatric patients. Though the present study contributes to stigma research in the Indian context, greater in-depth research is required to address these issues in other regions of India.

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