

# **‘They love me, but they don’t understand me’: Family support and stigmatisation of mental health service users in Gujarat, India**

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## **Abstract**

### **Background:**

Family life is a near-universal condition and a fundamental human right. It can also have a significant impact on mental health, including recovery from mental health conditions. In India, families play a considerable role, representing a source of social, cultural, religious and, often, financial support. However, families can also play a stigmatising role.

### **Aim:**

To examine the experiences of mental health service users (MHSUs) relating to stigma and support provided by family members and to consider ways in which family support can be improved.

### **Method:**

This is a qualitative study. A total of 17 residential MHSUs at the Ahmedabad Hospital for Mental Health were interviewed. The results were evaluated using thematic content analysis.

## **Results:**

The results revealed that all 17 MHSUs considered their families to be important sources of support, while 14 of the 17 MHSUs also experienced stigma emanating from their families. A total of 11 experienced lack of knowledge, 4 spoke of prejudicial attitudes and 5 mentioned discriminatory behaviours. There were important gender differences in experiences. MHSUs mentioned needs ranging from education and peer support for family members to financial support.

## **Conclusions:**

Families act both as sources of support and stigmatisation. Education needs are considerable, while the need for peer support for families and resources to aid families in supporting people with mental health conditions are also important considerations.

**Keywords** Stigma, support, family, human rights

## **Introduction**

Research has demonstrated that the family and community life of a mental health service user (MHSU) can have a significant impact on well-being (Karno et al., 1987; Lefley, 1998; Vaughn & Leff, 1976). Accordingly, family life is a near-universal phenomenon as well as a fundamental human right in terms of international instruments such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD; United Nations General Assembly, 2007). In India, the family of origin and the extended family play a considerable role in all aspects of life. Families represent a source of social, cultural, religious and, often, financial support (Kapur, 2000; Mane, 1993).

Stigma relating to mental health is well-documented. It can significantly impede access to care and support services, while also contributing to additional distress (Corrigan & Miller, 2004). Stigma can be a barrier in numerous ways, ranging from denial of work opportunities to marginalisation from social and cultural life (Mahomed & Stein, 2017). Stigmatisation of mental health conditions can also be a significant risk factor for worsened long-term outcomes (Dickerson, Sommerville, Orioni, Ringel, & Parente, 2002). Thornicroft, Rose, Kassam and Sartorius (2007) have conceptualised stigma as being made up of three inter-related problems, such as (a) ignorance, a problem of knowledge; (b) prejudice, a problem of attitudes and (c) discrimination, a problem of behaviours. The internalisation of negative attitudes is also a considerable problem. Self-stigma, sometimes emanating from families, can have negative effects on self-esteem, treatment outcomes and efforts to achieve life goals (Corrigan, Larson, & Rüsich, 2009; Corrigan & Watson, 2002).

There is a growing body of evidence from India suggesting that stigma is a significant barrier to the full realisation of the right to participate in the community. Stigma has been documented in a number of Indian studies (Chowdhury et al., 2000; Raguram, Weiss, Channabasavanna, & Devins, 1996; Thara & Srinivasan, 2000; Verghese & Beig, 1974), many of which have demonstrated the need for increased awareness-raising and the negative implications for MHSUs of stigmatisation (Chowdhury et al., 2000; Thara, Kamath, & Kumar, 2003; Thara & Srinivasan, 2000). While families can be important sources of support, there is also evidence suggesting that families may themselves be sources of stigma

relating to mental health conditions (Charles, Manoranjitham, & Jacob, 2007; Kapur, 2000; Wahl & Harman, 1989).

Having ratified the CRPD in 2007, India is bound by its provisions, including an obligation ‘to raise awareness throughout society, including at the family level ... and to foster respect for the rights and dignity of persons with disabilities’ (United Nations General Assembly, 2007, p. 8). Similarly, an obligation exists to ensure that discrimination by any person against persons with disabilities is curbed (United Nations General Assembly, 2007, p. 6). It is therefore necessary, in the context of an analysis of the lived experiences of MHSUs in India, to also be mindful of the ways in which the state can facilitate the realisation of their human rights.

The purpose of this study was to examine the experiences of MHSUs of support and stigmatisation emanating from family members. An additional consideration was also to investigate what potential assistance MHSUs viewed to be necessary for their families.

## **Method**

### ***Setting***

The Ahmedabad Hospital for Mental Health (Ahmedabad Hospital) was established in 1863 and has since expanded and been modified to accommodate a total of 317 residential users (217 male beds and 100 female beds located in 5 ‘closed wards’ and 2 ‘family wards’) as well as an outpatient department. According to facility records, occupancy is usually at 70%, and 80% of all admissions are voluntary. The facility houses chronic as well as acute users, with varying Axis I diagnoses that include psychotic, mood and anxiety conditions, and with a duration of stay ranging from about 10 days to a handful of users who have resided at the facility for over 10 years due to the presence of chronic psychotic symptoms. A programme entitled ‘Saathi’ was established, for family members of residential and outpatient MHSUs. Saathi meets fortnightly, providing education through the use of community mental health workers and facilitating peer support programmes for all MHSUs and family members wish to attend.

### ***Sample***

The sample consisted of 17 residential (in-patient) MHSUs at Ahmedabad Hospital. There were nine male users and eight female users, ranging in age from 22 to 64 years, with Axis I diagnoses of psychotic (10), mood (6) or anxiety conditions (1). All participants had obtained some high school education, with two (one male and one female) having obtained a higher vocational training certificate and one (male) having obtained a university degree. To ensure that informed consent could be obtained in a manner compliant with ethical regulations, only non-acute MHSUs (i.e. Patients who were not housed in acute wards) were approached to participate at times when there were no other activities planned. Patients who agreed were included in the sample. A total of 17 was the maximum number of participants based on time and resource constraints.

### ***Data collection***

MHSUs were interviewed using a semi-structured interview protocol that explored their experiences of family support and stigmatisation. The protocol consisted of 12 questions, 10

of which were open-ended to allow for elaboration. Interviews were conducted in person with the aid of an interpreter, a MHSU himself (D.H.), who received training prior to the commencement of the study. The interviews each lasted between 30 and 60 minutes and were audio recorded. Ethics approval was obtained from the Institutional Review Board of Ahmedabad Hospital. Prior informed consent was obtained using verbal and written information.

### ***Analysis***

The recorded interviews were transcribed verbatim and then coded manually in a process of thematic content analysis. The content analysis procedure was iterative in nature, seeking for emergent themes that provided meaning and structure for the overall data set. Coding was done by the interviewer (F.M.) and an independent coder (J.N.B.), who were provided with anonymised transcripts. Cronbach's alpha was computed to ascertain inter-rater reliability.

### **Results**

Cronbach's alpha revealed an inter-rater reliability coefficient of 0.81, demonstrating a high level of agreement. The results are presented as four themes below.

#### ***Families as sources of support***

The results showed that family members acted as sources of support for the MHSUs interviewed in a variety of ways. All of the MHSUs interviewed noted that emotional and moral support provided by family members was a significant motivating factor. Supports included financial as well as emotional assistance. One MHSU stated,

I work sometimes, but without my brother, I would not be able to survive. (M, 40)

This individual was referring to the financial support provided by his brother, and the fact that full-time employment was not an option for him due to his condition. MHSUs were often acutely aware of the additional stress that this placed on family members. As one individual stated,

I am concerned about being a burden. I want to get better so I can get a job and move out of my parents' house. (M, 37)

This suggests that recovery may, at times, be motivated by the desire for self-sufficiency, although it is perhaps also indicative of the fact that some MHSUs feel a pressure, whether self-imposed or imposed by others, to be more financially independent.

The encouragement of families was said to play a significant role in the well-being of MHSUs. As one speaker noted,

I think one of the main reasons I am getting better is my family. (F, 52)

#### ***Families as a source of stigma***

MHSUs mentioned that, while most family members were very supportive, others tended to be less so. As one person stated,

My sister tells me to be patient. She gives me support and encouragement, but I know that her husband doesn't like me. (F, 25)

Importantly, this individual noted that the effect of these disparate responses were sometimes a considerable source of conflict for all concerned. Therefore, differentials within families in terms of how they respond to family members with mental health conditions can be considerable stressors not only for the MHSU him or herself but also within the family as a separate entity entirely.

Stigmatisation by family members, in its various forms, was mentioned by 14 of the 17 participants. Around 11 participants spoke only of the lack of knowledge or understanding of mental health challenges as being the primary source of stigmatisation. This resulted in various forms of stigmatisation, ranging from misunderstanding the needs of individual MHSUs to recommending or supporting remedies that were inappropriate in the view of the MHSUs themselves. For example, one individual stated,

My parents don't want me to go out or to be left alone because they think I need to be supervised all the time, even when the doctor tells them to let me be more free. (M, 28)

Another states,

My mother always tells me that I am this way because I didn't get married early. She thinks if I get married, everything will be okay. (F, 39)

These statements reflect a potential lack of understanding regarding the aetiology and severity of mental health conditions. However, they do not necessarily reflect the more prejudicial attitudes often associated with mental health stigma. That is not to say, however, that these were not evident as well. Four of the 17 respondents spoke about prejudice as a source of stigma as well. For example, one MHSU said of his siblings and the broader community that,

They avoid me ... like I am untouchable. (M, 36)

Another spoke of stigmatising attitudes as a considerable source of additional stress:

When I know that [my family members] think this way, where can I go? (F, 44)

The internalisation of some of these negative attitudes (self-stigma) was also mentioned. For example,

If they tell me I'm mad and useless every day, sometimes I believe it. (F, 27)

These prejudicial attitudes also result in more overt forms of discrimination, with 5 of the 17 participants noting that they had experienced discriminatory behaviours emanating from family members. For example, one MHSU said,

Each time I go home, they call me mad and they tell me to go back to the mad hospital because outside I am useless. (M, 45)

Another noted that,

There are times when I am afraid to be among my family members because they call me names or they threaten me ... or they will even leave me outside. (F, 60)

### *Gender differences*

There were some gender differentials in terms of how support and stigma emanating from family members manifested in the lives of participants. A key feature of the framing of stigmatisation among male interviewees was around the effect that a mental health condition might have on the ability to work or to be self-sufficient. One respondent states,

I will only earn my family's respect when they see me with a job again. (M, 53)

Another male respondent stated even more pointedly,

Without a job, a man is nothing. (M, 35)

Coupled with this belief, there was a sense that workplaces may view mental health conditions as a risk and that this perspective could in turn impact on the family dynamic. To illustrate,

My parents think because of my [condition], no one will give me a job. This is why they want me to get better. (M, 27)

By comparison, female respondents spoke about the effect that a mental health condition can have on their marriageability or suitability as mothers. One MHSU, who had been divorced by her husband because of her admission, said,

This illness took away my husband. (F, 31)

Another described a process by which her family decided to prevent her from raising her daughter after her divorce:

They came and they told me that I shouldn't be alone with [my daughter] because I can't look after her. (F, 40)

For those not married, there is a concern that the disability may make it impossible to find a suitable spouse. As one participant recounted,

My parents worry that no one will marry me because I am sick ... sometimes I worry about it too. (F, 26)

While these gender differences may reflect broader societal norms, they also illustrate the way that these norms can coalesce with stigmatising attitudes and behaviours in the experiences of MHSUs.

### *Family needs*

Participants voiced some insights regarding their families' needs for greater support from the state and their communities. Perhaps chief among these was a need for further information and education to enable families in their efforts to assist MHSUs. These information and education needs were diverse, ranging from a desire for more education regarding mental

health conditions themselves to information regarding what services are available and regarding the human rights of MHSUs. One respondent noted,

I think if they understood it better, they would know how to take care of me. (M, 64)

Some participants also voiced a need for support groups for family members of MHSUs, noting the stressors that may arise and the potential for stigmatisation of entire families by the broader community. As one MHSU said,

It is difficult for them. Sometimes they need [support]. (F, 26)

The Saathi programme, which seeks to address both the need for information and for community support, was mentioned as a useful way in which family members engaged with the subject of mental health. One MHSU noted,

Without [Saathi], they wouldn't know anything. [M, 36]

Even so, some family members were either unwilling or unable to attend the Saathi meetings. The reasons mentioned included the perception that some families 'don't care', as well as geographical, financial and work constraints. In respect of resource needs, some MHSUs highlighted the need for financial support due to the costs associated with caring for a relative. A participant stated,

The government should remember that [caring for family members with mental health conditions] is expensive. (M, 42)

It was also suggested that addressing this resource need could also substantially attend to some of the negative attitudes described earlier, by reducing the financial 'burden' of caring for a relative with a mental health condition. Therefore, mitigating the financial costs of caring for family members can be a potential avenue through which stigma can be reduced as well.

## **Discussion**

This study demonstrates that family members can be sources of support and stigmatisation at the same time. It is encouraging that all users interviewed considered their families to be important sources of support and encouragement. This included emotional as well as financial assistance, although the latter can create an additional 'burden', potentially being a source of discord.

Notwithstanding the support provided by family members, interviewees also experienced stigma emanating from their families. The most common aspect of the stigmatising experience was what Thornicroft et al. (2007) refer to as 'ignorance' or a lack of knowledge regarding mental health. This is in keeping with other research that has shown that false attributions and problematic explanatory models for mental health conditions can be sources of stigma within families (Charles et al., 2007). It is also further corroborated by the fact that MHSUs cited a significant need for more information for family members as an important potential contribution. Considering the obligation arising from the CRPD to raise awareness and promote the rights of people with disabilities (including MHSUs), this is an important and necessary intervention.

In addition to the ‘ignorance’ mentioned, the other two aspects of Thornicroft et al.’s (2007) definition of stigma were also present in the lived experiences of MHSUs. Negative attitudes of family members (‘prejudice’) were cited as a challenge, with MHSUs being acutely aware of the way in which they were viewed. It has been noted that the experience of being stigmatised in such a way can lead to self-stigma, or the internalisation of these negative attitudes (Corrigan & Watson, 2002). This may negatively affect the recovery of an MHSU, suggesting that addressing the negative attitudes of family members is an important avenue through which improved mental health outcomes might be realised (Corrigan & Watson, 2002).

The third component of stigma consists of problematic behaviours (‘discrimination’). This, too, was experienced by a proportion of respondents, ranging from exclusion to abuse and neglect. The experience of discrimination, too, can have a considerable negative effect on mental health outcomes (Kessler, Mickelson, & Williams, 1999). This necessitates a response to familial discrimination to prevent further distress and adverse outcomes.

Gender differences between participants’ experiences of support and stigmatisation were also notable. For male participants, a considerable source of stigma arose out of the effect that a mental health condition can have on employability or productivity. This reflects an important social norm in India (Jeffrey, 2008). Similarly, female MHSUs experienced specific forms of stigmatisation emanating from family members. These, too, related to social norms in India, whereby a great deal of worth is attached to marriageability and the perceived ability to parent children (Mukhopadhyay and Seymour, 1994). Family members expressed concerns about the effect that a mental health condition might have on the attainment of these desired outcomes, and MHSUs themselves acknowledged the challenges associated with attempting to fulfil these aspirations once diagnosed. This is a complex dynamic, but it may be necessary to consider ways in which to address beliefs about the inability or undesirability for marriage and child-rearing of women with mental health conditions at broader social levels.

There were also some needs expressed by MHSUs, as they perceived their families’ stressors. The need for information and education around mental health was articulated, the suggestion being that families often wished to offer the supports needed but sometimes did not know how to do so. Similarly, addressing the knowledge barrier can be a useful way in which to address false attributions and problematic explanatory models of mental health conditions, in the process offering an avenue through which stigma can be reduced (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012).

It is important to note that families may themselves be subjected to stigma based on one member’s mental health condition. Communities may misattribute mental health conditions based on problematic explanatory models or may overtly marginalise the entire family unit because of stigmatised beliefs and attitudes. This, too, has the potential for contributing to adverse mental health outcomes and to discord within families (Charles et al., 2007). Tackling community and societal-level forms of stigma by addressing problematic explanatory models and providing human rights education can significantly alter these effects (Corrigan et al., 2012), while also meeting the country’s commitments under the CRPD. To diminish the effects of isolation and to ensure that family members were able to offer support to each other in the face of their unique experiences, participants recognised a need for peer support initiatives for family members.

It is worth highlighting the Saathi programme and its dual goals of offering information to families, facilitated by community mental health workers, while also developing a peer support mechanism for family members of people with mental health conditions. This was seen as an important positive development by the MHSUs interviewed, illustrating that it may not only address the needs of family members but may also be a source of indirect support to MHSUs themselves. There were some barriers noted to participation, however, including resource constraints to attend the meetings, geographical distance and work obligations. These were coupled with a perception among some respondents that their family members ‘don’t care’. Some of these barriers will be difficult to address, but the potential of the Saathi model is clear, and the fact that it is potential is seen by MHSUs themselves is a significant indication of its possible effect on mental health outcomes.

Participants also noted that there was a need for intervention on the part of the state insofar as addressing the ‘burden’ of caring for a family member with a mental health condition was concerned. Financial supports can be useful ways to address the family’s needs, while also reducing discord and the stigmatisation of MHSUs who may be seen as a financial drain on resources. Considering the obligation upon the state to ensure full and equal participation of people with disabilities in all sectors of society, as contained in the CRPD, efforts to address barriers to such participation, including financial barriers, should be considered essential interventions.

This study aimed to develop an understanding of the way in which family members can be both sources of support and sources of stigmatisation of people living with mental health conditions. It examined the experiences of MHSUs themselves and elicited results with potential policy implications. It also highlights some important avenues for future research, including examination of the experiences of outpatient MHSUs and their families, in-depth research involving family members as respondents and an exploration of the work of the Saathi programme. Admittedly, the fact that this study was unable to address all of these questions in-depth is indeed a limitation that could be rectified in future inquiries. Similarly, time and resource constraints meant that the sample size for this research was limited, and further inquiry with a broader sample would be a useful exercise to validate these results.

This article demonstrates that there is potential for addressing the needs of MHSUs and their families through practical means that will contribute to improved mental health outcomes of users themselves and to the lives of their families. Addressing the stigmatisation of mental health conditions is a complex challenge that requires responses to engage with knowledge, attitudes and behaviours. The fact that an obligation exists in the CRPD to raise awareness of the rights of people with disabilities and to address barriers to equal participation mean that this challenge will need to be met with action. The fact that stigma within family systems is a common challenge may be cause for concern, but the strength and encouragement that MHSUs derive from their families should also be celebrated and supported as the manifestation of the fundamental right to family life.

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