



Experiences of stigma and discrimination of people with schizophrenia in India



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ABSTRACT

Stigma contributes greatly to the burden of schizophrenia and is a major obstacle to recovery, yet, little is known about the subjective experiences of those directly affected in low and middle income countries. This paper aims to describe the experiences of stigma and discrimination of people living with schizophrenia (PLS) in three sites in India and to identify factors influencing negative discrimination.

The study used mixed methods and was nested in a randomised controlled trial of community care for schizophrenia. Between November 2009 and October 2010, data on four aspects of stigma experienced by PLS and several clinical variables were collected from 282 PLS and 282 caregivers and analysed using multivariate regression. In addition, in-depth-interviews with PLS and caregivers (36 each) were carried out and analysed using thematic analysis.

Quantitative findings indicate that experiences of negative discrimination were reported less commonly (42%) than more internalised forms of stigma experience such as a sense of alienation (79%) and significantly less often than in studies carried out elsewhere. Experiences of negative discrimination were independently predicted by higher levels of positive symptoms of schizophrenia, lower levels of negative symptoms of schizophrenia, higher caregiver knowledge about symptomatology, lower PLS age and not having a source of drinking water in the home. Qualitative findings illustrate the major impact of stigma on 'what matters most' in the lives of PLS and highlight three key domains influencing the themes of 'negative reactions' and 'negative views and feelings about the self', i.e., 'others finding out', 'behaviours and manifestations of the illness' and 'reduced ability to meet role expectations'.

Findings have implications for conceptualising and measuring stigma and add to the rationale for enhancing psycho-social interventions to support those facing discrimination. Findings also highlight the importance of addressing public stigma and achieving higher level social and political structural change.

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1. Introduction

The stigma associated with mental illness contributes significantly to the burden of schizophrenia. Subjective accounts of persons affected by mental illness testify that its effects are often perceived as more burdensome and distressing than the primary condition itself (Thornicroft, 2006). The term stigma refers to "a

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social devaluation of a person” (Thara and Srinivasan, 2000, p. 135) due to an “attribute that is deeply discrediting” (Goffmann, 1963, p.3), and can be conceptualised as consisting of “problems of ignorance, prejudice, and discrimination” (Thornicroft, 2006, p. 182). Discrimination leads to disadvantages in many aspects of life including personal relationships, education and work. As a result of internalised stigma, some people with mental illness may further accept the discrediting prejudices held against them and lose self-esteem, leading to feelings of shame, a sense of alienation and social withdrawal (Livingston and Boyd, 2010; Ritscher et al., 2003). Therefore, people with mental illness may expect to be treated in a discriminatory way (‘anticipated discrimination’) and try to hide their illness or stop themselves from taking up opportunities (Ritscher et al., 2003; Thornicroft, 2006).

While it is widely accepted that stigma constitutes a universal phenomenon, experiences of stigma and discrimination are local (Murthy, 2002). Yang et al. point out that “across cultures, the meanings, practices and outcomes of stigma differ, even when we find stigmatisation to be a powerful and often preferred response to illness, disability and difference” (Yang et al., 2007, p. 1528).

Although there is now a large evidence base on descriptive aspects of stigma, the great majority of these studies have been carried out in high-income settings (Livingston and Boyd, 2010; Mestdagh and Hansen, 2014). Given the importance of context-specific factors in shaping stigma, research is needed to understand which aspects of the experience of stigma are most common and burdensome in the Indian context and which determinants are relevant and potentially amenable. The aim of our study was to contribute to such context-specific understanding of stigma and to inform the design of future anti-stigma interventions in India.

Similar to studies in other parts of the world (Thornicroft, 2006), research from India has illustrated high levels of stigmatising attitudes towards PLS among community members and health staff (see Loganathan and Murthy, 2008 for a summary). Impact of stigma on help-seeking and other aspects of health has been shown to be high (Shidhaye and Kermode, 2013). However, much less is known about the subjective experiences of PLS in India. In one particularly informative Indian study PLS reported being ridiculed, avoided or looked down upon. A few were given stale food, stopped from leaving the house, beaten or hit with stones. Some spoke about lack of respect from family members (Loganathan and Murthy, 2008). Men experienced stigma most strongly in regard to employment, and women in relation to marriage and childbirth (Loganathan and Murthy, 2011). In another study, stigmatising reactions were often enacted by family members and neighbours (Murthy, 2005).

Women’s experiences of stigma were also explored in a qualitative study, which involved 76 women with schizophrenia whose marriages had broken. Many had been abandoned by their husbands and only very few received financial support. Some had experienced beating and neglect. Several felt a burden to their parents, which was reinforced by hostility from family members (Thara et al., 2003).

Little is known about the determinants of subjective experiences of stigma associated with in India. While research from high-income countries (HIC) indicates that symptom severity is one of the most consistently identified determinants of experienced stigma (Livingston and Boyd, 2010), research from India on this association is scarce and has shown conflicting results (Charles et al., 2007; Loganathan and Murthy, 2008; Raguram et al., 2004). Yet, the importance of illness features and behaviours in determining social reactions has been highlighted (Raguram et al., 2004; Weiss et al., 2001).

As Yang et al. have noted, a crucial condition for understanding the experience of stigma in different cultural contexts is

understanding what is ‘at stake’ or ‘what matters most’ (Yang et al., 2014a,b, 2007). No studies so far have examined stigma in India specifically from this perspective.

This study employed mixed methods to describe the experiences of stigma and discrimination of PLS in three diverse sites in India with a focus on ‘what matters most’ and on information that may be relevant to the development of interventions.

2. Methods

2.1. Setting

The study was nested in a randomised controlled trial of collaborative community care for people with schizophrenia in India (COPSI Trial) and implemented in three diverse settings in India—in rural Tamil Nadu by the Schizophrenia Research Foundation (SCARF) and in two mixed urban and rural sites in Goa and Maharashtra (Satara) by the NGOs ‘Sangath’, ‘Parivartan’ and ‘Nirmittaa’ in collaboration with private psychiatrists (Balaji et al., 2012a,b; Chatterjee et al., 2011, 2014a,b). In Tamil Nadu, psychiatric care was provided through the rural clinics of SCARF and in Satara and Goa by private psychiatrists. Full characteristics of the study sites have been described elsewhere (Chatterjee et al., 2011).

The study used cross-sectional data collected at entry into the trial (between November 2009 and October 2010) and employed a concurrent mixed methods design, combining quantitative data from all PLS and caregivers in the trial (282 PLS and 282 primary caregivers) and qualitative data from a purposively selected subsample (36 PLS and 36 caregivers). This paper presents integrated study findings on stigma faced by PLS, drawing on quantitative assessments with PLS and qualitative interviews with PLS and caregivers. Findings on caregivers’ own experiences of stigma will be reported separately.

2.2. Recruitment and sampling

The quantitative study included the total sample of participant dyads recruited for the COPSI trial ($n = 282$), with 105 dyads from Tamil Nadu, 92 from Goa and 85 from Satara. In Goa and Satara, PLS were recruited from the clinical practices of collaborating psychiatrists; in Tamil Nadu, they were identified through a community survey and referred to the clinics of SCARF. For each PLS, one primary caregiver was recruited.

Eligibility criteria were i) 16–60 years old, ii) a primary diagnosis of schizophrenia as per ICD-10 DCR criteria (WHO, 1992) (diagnosed by the treating psychiatrist), iii) illness duration of at least 12 months and an overall moderate severity of the illness based on the Clinical Global Impression-Schizophrenia (CGI-SCH) (Haro et al., 2003) scale and iv) residence within the catchment area for the duration of the study.

A subsample of 36 PLS - caregiver dyads from those already recruited for the trial was selected for participation in the qualitative study component. A purposive sampling technique was applied, aiming to ensure adequate sample variability for PLS gender, severity of illness according to the PANSS (Kay et al., 1987), highest household education level and research site. To facilitate the in-depth study of experienced stigma, there was a slight intentional overrepresentation of PLS reporting higher levels of negative discrimination on the Discrimination and Stigma Scale (DISC) (Brohan et al., 2013).

Informed consent was obtained from all PLS and caregivers taking part, with an additional level of consent provided by those participating in qualitative interviews (Chatterjee et al., in submission; Chatterjee et al., 2011)). Ethics approval was obtained from the Institutional Review Boards at SCARF and Sangath in India,

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