



Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India



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ABSTRACT

Stigma associated with schizophrenia significantly affects family caregivers, yet few studies have examined the nature and determinants of family stigma and its relationship to their knowledge about the condition. This paper describes the experiences and determinants of stigma reported by the primary caregivers of people living with schizophrenia (PLS) in India. The study used mixed methods and was nested in a randomised controlled trial of community care for people with schizophrenia. Between November 2009 and October 2010, data on caregiver stigma and functional outcomes were collected from a sample of 282 PLS–caregiver dyads. In addition, 36 in-depth-interviews were conducted with caregivers. Quantitative findings indicate that ‘high caregiver stigma’ was reported by a significant minority of caregivers (21%) and that many felt uncomfortable to disclose their family member’s condition (45%). Caregiver stigma was independently associated with higher levels of positive symptoms of schizophrenia, higher levels of disability, younger PLS age, household education at secondary school level and research site. Knowledge about schizophrenia was not associated with caregiver stigma. Qualitative data illustrate the various ways in which stigma affected the lives of family caregivers and reveal relevant links between caregiver-stigma related themes (‘others finding out’, ‘negative reactions’ and ‘negative feelings and views about the self’) and other themes in the data.

Findings highlight the need for interventions that address both the needs of PLS and their family caregivers. Qualitative data also illustrate the complexities surrounding the relationship between knowledge and stigma and suggest that providing ‘knowledge about schizophrenia’ may influence the process of stigmatisation in both positive and negative ways. We posit that educational interventions need to consider context-specific factors when choosing anti-stigma-messages to be conveyed. Our findings suggest that messages such as ‘recovery is possible’ and ‘no-one is to blame’ may be more helpful than focusing on bio-medical knowledge alone.

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1. Introduction

Problems related to stigma do not only affect persons suffering from mental illness but also families (Corrigan et al., 2006; Phelan et al., 1998). In his seminal work on stigma in the 1960s, Goffman

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already reflected upon the stigma that spills over to families, coining the term ‘courtesy stigma’ (Goffmann, 1963). The negative impact of this form of stigma (which we will refer to as ‘family stigma’) may be particularly marked in settings where family cohesion is high. In India, as in many low and middle-income countries (LAMIC), most people living with schizophrenia (PLS) live with their families and rely on them for both economic support and everyday care (Thara, 1993). Thus, family members are closely involved in most aspects of PLS’ care and often maintain control of help-seeking and treatment decisions, assuming many of the roles filled by health or social care staff in high-income country (HIC) settings (Nunley, 1998). The high quality of family support provided to many PLS in India is likely to reflect a widely held social norm that no one should have to live alone because of their illness (Thara, 1993).

At the same time, studies in India also document how, in the absence of adequate health and social care, particularly in life domains such as finances, family relationships, well-being and health, family members of PLS cope with enormous caregiver burden (Kumar et al., 2015). Stigma adds to the burden of caregiving and affects the lives of family members of PLS in multiple ways. For example, research from South India has found that family caregivers of PLS were often concerned that other family members would not be able to marry or that friends, relatives or neighbours might avoid or treat them differently (Raguram et al., 2004; Thara et al., 2003; Thara and Srinivasan, 2000). Similar findings have been reported for other LAMIC (Chien et al., 2014; Phillips et al., 2002; Shibre et al., 2001) and several HIC (Larson and Corrigan, 2008).

Lack of knowledge about mental illness has been described as one of the components of the stigma construct itself, for example in Thornicroft’s conceptualisation of stigma as an overarching construct consisting of problems of knowledge (ignorance), attitudes (prejudice) and behaviour (discrimination) (Thornicroft, 2006). Many anti-stigma interventions aim to improve knowledge about mental illness (Mehta et al., 2015) and health care interventions for family members of PLS often focus on ‘knowledge about schizophrenia’ (Sin and Norman, 2013). Poorer knowledge about mental illness has been linked to stigmatising attitudes in several studies (Jorm et al., 2006; Thornicroft, 2006), but little is known about the links between knowledge about mental illness and subjective stigma experience, particularly among family members. A better understanding of this relationship may inform efforts to reduce the impact of stigma, for example by suggesting messages to be conveyed in educational interventions (Clement et al., 2010).

Findings on the experiences of stigma of PLS taking part in this study have been reported previously in this journal (Koschorke et al., 2014). The aim of the present paper is to describe caregivers’ own experiences of stigma, and the factors influencing these experiences in India. We also examine the hypothesis that caregivers with lower levels of knowledge about schizophrenia experience higher levels of stigma.

2. Methods

2.1. Setting

The study was nested in a randomised controlled trial of collaborative community care for PLS in India (COPSI trial) which was implemented in three diverse settings: in rural Tamil Nadu by the Schizophrenia Research Foundation (SCARF), and in two mixed urban and rural sites, Goa and Satara (Maharashtra), by the NGOs ‘Sangath’, ‘Parivarthan’ and ‘Nirmitttee’ in collaboration with private psychiatrists. Methods and findings of the COPSI trial have been

described elsewhere (Balaji et al., 2012a, 2012b; Chatterjee et al., 2015, 2011, 2014). The nested study on stigma used cross-sectional data collected at the point of entry into the trial and employed a mixed-methods approach, combining quantitative data from all PLS and caregivers in the trial and qualitative data from a purposively selected subsample of PLS and caregivers. The methods used have been described in detail in our publication on PLS’ experiences of stigma (Koschorke et al., 2014), and will therefore only be summarised briefly here.

2.2. Recruitment and sampling

The quantitative sample for the study comprised all PLS and caregivers recruited for the COPSI trial ($n = 282$ PLS-caregiver dyads). Eligibility criteria for PLS were: i) age 16–60 years; ii) a primary diagnosis of schizophrenia by ICD-10 DCR criteria (WHO, 1992); 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) scale rating (Haro et al., 2003); and iv) residing within the study catchment area for the duration of the study. One primary caregiver (usually the family member most closely involved with the PLS in everyday life) was recruited for each PLS.

For the qualitative study component, a purposive sampling technique was utilised in an effort to ensure adequate sample variability for PLS gender, severity of illness according to the PANSS (Kay et al., 1987), highest education level in the household and research site. In order to facilitate the in-depth study of experiences of stigma and discrimination, there was oversampling of dyads in which PLS reported higher levels of negative discrimination according to the DISC negative discrimination scale (Thornicroft et al., 2009). Overall, 36 PLS-caregiver dyads were recruited to allow for adequate numbers in each sampling category.

2.3. Data collection

Quantitative data on caregiver stigma were collected using an adapted version of the stigma section of the Family Interview Schedule, which had been developed for the International Study of Schizophrenia (Sartorius and Janca, 1996) and previously used in a similar population in India (Thara and Srinivasan, 2000). It comprised of 10 items on stigma experience (e.g. ‘you worried that your neighbours would treat you differently’) that were scored from ‘not at all’ to ‘a lot’ (scores 0–3). In addition, caregivers rated their willingness to disclose their relative’s illness on a single item scored on a Likert scale ranging from 1–5 (‘In general, how comfortable would you feel talking to a friend or family member about your ill family member’s mental health, for example telling them he/she has a mental health diagnosis and how it affects him/her and the family?’), adapted from a similar item for people with mental illness (Koschorke et al., 2014; TNS UK Care Services Improvement Partnership, 2009). Caregivers knowledge about schizophrenia was measured using the Knowledge About Schizophrenia Interview (KASI) (Barrowclough et al., 1987), which assesses six domains of understanding: Knowledge about diagnosis, symptomatology, aetiology, medication, course and prognosis and management.

A standardised process of translation and validation of tools was followed, as has been described previously (Chatterjee et al., 2011, 2014). Measures on stigma underwent an additional process of validation through focus group discussions involving PLS, caregiver and mental health staff representatives. Three items of the Family Interview Schedule (two on coping strategies and one on general illness impact) were removed to ensure all items used related directly to experiences of stigma.

Data collection took place between November 2009 and October

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