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## Stigma and discrimination experienced by people with schizophrenia living in the community in Guangzhou, China



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#### ABSTRACT

The aims of this study were to investigate experienced stigma and discrimination and their associated factors in people with schizophrenia who live in the community in Guangzhou, China. A total of 384 people with schizophrenia were randomly recruited from four districts of Guangzhou and completed the scales and questionnaires: Internalized Stigma of Mental Illness scale (ISMI), Self-Esteem Scale (SES), Discrimination and Stigma Scale (DISC-12), Brief Psychiatric Rating Scale (BPRS), PANSS negative scale (PANSS-N), Global Assessment of Functioning (GAF) and Schizophrenia Quality of Life Scale (SQLS). Insight and medication compliance were evaluated by psychiatrists. Data were analyzed by using descriptive statistics, Pearson correlation and multivariable linear regression. We found a significant positive correlation between BPRS score and PANSS-N score, GAF score was significantly negative correlated with SQLS score, Insight score was significantly negative correlated with medication compliance score, ISMI score was significantly positive correlated with SES score and experienced discrimination score. Multivariable linear regression found SQLS, SES and experienced discrimination were the main independent variables of ISMI and experienced discrimination was the most important factor of ISMI. Our findings suggest that people with schizophrenia often experienced stigma and discrimination in this Chinese population, and more anti-stigma interventions should be provided.

#### 1. Introduction

Schizophrenia is a serious and highly stigmatized mental disorder (Link et al., 2006; Sharaf et al., 2012). People with schizophrenia are often incorrectly thought to be more dangerous, aggressive and prone to crime (Yılmaz et al., 2015). The condition has a profound effect on the individuals affected, for example, high rates of unemployment and a reduced life expectancy of around 10–20 years (Owen et al., 2016). Schizophrenia accounts for 7.4% of global disability-adjusted life years (DALYs) reported in the 2010 Global Burden of Disease Study (Patel et al., 2014). Stigma and discrimination are complicating features of psychiatric disorders and treatment, especially for schizophrenia.

Stigma was first defined as "an attribute that is deeply discrediting" (Semrau et al., 2015); however, this concept received criticism for being too individually focused and loosely defined. Recently, it is documented that stigma contains labeling, stereotyping, separation, status loss, and discrimination (Link et al., 2001; Omori et al., 2014).

Moreover, Corrigan categorized stigma as public stigma and self-stigma (Brohan et al., 2010b). Stigma has been defined as comprising three elements: problems of knowledge (ignorance or misinformation), problems of attitudes (prejudice), and problems of behaviour (discrimination) (Brohan et al., 2010b; Mosanya et al., 2014; Thornicroft et al., 2007). This conceptualisation provides a new direction focusing on how discrimination is experienced and establishing an evidence base of effective interventions.

Stigma and discrimination have been associated with poor quality of life, low self-esteem, and social withdrawal in people with schizophrenia (Brohan et al., 2011; Rusch et al., 2005). As a result, people with schizophrenia often try to hide their illness or stop themselves from taking on opportunities (Koschorke et al., 2014). Discrimination also disadvantages individuals in several ways, such as unemployment, loss of income, reduced access to education, housing or health care (Thornicroft et al., 2016; Yin et al., 2014). Patients with schizophrenia may have less investment of health-care resources allocated than those

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with physical illnesses, and a low use of diagnostic procedures when the patients have physical illness (Sartorius, 2007). With such a poor health care, people with schizophrenia might delay or stop seeking treatment or terminate treatment prematurely. Arguably, sigma and discrimination are the most important obstacles to the provision of mental health care and to the development of mental health programs (Beldie et al., 2012; Sartorius, 2013).

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The way people experienced stigma and discrimination may be different because of the different cultural contexts (Koschorke et al., 2014). From the historical perspective, people with mental disorders in Europe were sometimes thought to be possessed by "evil spirits", which may well have been associated with high levels of stigma and discrimination. However, people would receive relatively human treatment in some Muslim societies. The main sources of reported experienced stigma and discrimination recently are from high-income countries (HICs), displaying high rates of stigma and discrimination in making friends, job-seeking (Thornicroft et al., 2009), and self-stigma (Brohan et al., 2010a). For the negative consequences of stigma and discrimination, schizophrenia has been selected as the central focus of the World Psychiatric Association's global anti-stigma programme entitled "Open the Doors" (Bifftu et al., 2014; Stuart, 2008). In order to deliver primary health-care effectively, HICs have executed community based programs, which rely on shifting tasks from specialists to nonspecialists (Kakuma et al., 2011).

However, people with mental illness who live in the community (where services tend to be more established) still experience stigma and discrimination (Semrau et al., 2011). While there still a lack of studies in low- and middle-income countries (LMICs), where about 85% of the world's population live (Jacob et al., 2007). One international study using population-wide data from 16 countries found even higher rates of reported stigma among people with mental disorders in developing (31.2%) than in developed (20%) countries (Alonso et al., 2008).

In China, an estimated 173 million Chinese people have been diagnosed with psychiatric disorder, but among them 158 million have never received any treatment (Xiang et al., 2012). Most studies have focused on investigation of social stigma in people with schizophrenia (Lee et al., 2005), and the knowledge and attitudes of medical students (Rong et al., 2011) or family members (Phillips et al., 2002) toward patients with mental illness. Few studies have emphasized behaviors that help people to deal with the stigma and discrimination of mental illness in LMICs.

Guangzhou is the capital city of Guangdong province, near to Hong Kong and the adjusted lifetime prevalence rate of mental disorders is about 15.76% (Zhao et al., 2009). More than 20,000 patients with schizophrenia are registered in the system of Guangzhou severe mental disorders management database. Guangzhou Huiai Hospital (also known as Guangzhou Brain Hospital) has been in charge of management of people with mental illness for more than half a century. Several studies have reported the level of stigma (Li et al., 2014b) and the knowledge and attitude among community mental health staff (Li et al., 2014a). However, no assessment about the experiences of stigma, especially discrimination among people with schizophrenia in community has been reported.

The aims of this study therefore are to assess the experiences of stigma and discrimination among individuals with schizophrenia in community of Guangzhou, China, and to investigate the factors associated with a higher likelihood of experiencing stigma and discrimination. Also, we want to emphasize that this study is a part of the Policy, Training, Services and Assessment (PTSA), also called "Guangzhou Mental Health Model" (Li et al., 2015), which aims at overcoming the deficiency of the serious human resource shortage and huge treatment gap, and providing effective community mental health services in real situations. In this way, the study will provide baseline information for the further research of interventions.

#### 2. Method

#### 2.1. Study design and participants

The cross-sectional study was conducted at Guangzhou Huiai Hospital in a sample of patients with schizophrenia, who were registered in the system of Guangzhou severe mental disorders management database. More than 50,000 people have been registered in the system, about 20,000 of whom have a clinical diagnosis of schizophrenia. We first divided the 12 administrative districts in Guangzhou City into 2 clusters (6 central districts and 6 suburban districts) according to their geographical location. Then we randomly chose two central districts (Tianhe and Liwan) and two suburban districts (Huadu and Nansha) from the 2 clusters. The sample size was calculated by the formula (Li et al., 2015). And then 120 participants from each district were randomly recruited. All participants were screened based on the inclusion criteria and exclusion criteria described below.

Inclusion criteria included: (1) Participants were diagnosed as having schizophrenia by certified psychiatrists according to ICD-10 DCR criteria; (2) Aged between 18 and 50 years old; (3) Participants had at least full primary school education; (4) Participants were taking antipsychotic drugs, and had a stable condition; (5) Participants lived in the local community during the study. Exclusion criteria included: (1) hospitalized due to substance abuse prior to the study, acute risk of suicide and violence, severely intellectually challenged with learning difficulties; (2) severe and unstable physical disease such as cerebrovascular diseases, etc; (3) patients who were pregnant and / or lactating. A total of 384 patients were enrolled. 96 participants were excluded, and the main reasons were: (1) though the diagnosis in the computer system was given as schizophrenia, this was not the clinical diagnosis given about the project senior psychiatric staff; (2) patients with serious physical comorbid conditions; or (3) those who did not consent to participate.

The survey was conducted from April 2015 to July 2015. The study protocol was approved by Research Ethics Committee of Guangzhou Huiai Hospital (Number 012, 2015). Written informed consent was obtained from each participant after the procedure had been fully explained.

#### 2.2. Measurements

The Brief Psychiatric Rating Scale (BPRS): developed by Overall and Gorham, was used to assess the severity and change of psychotic and some depressive symptoms in schizophrenia and other psychotic disorders (Altintas et al., 2016). The scale has been translated into Chinese and is the most frequently used measure of assessing psychopathology. It has good validity and inter-rater reliability (Zhang et al., 1983). It consists of 18 items, each being rated for symptom severity ranging from 1 (not present) to 7 (extremely severe). Factor analysis results suggested different symptom clusters in this scale: the set of negative symptoms (emotional withdrawal, blunted affect, and motor retardation) and the set of positive symptoms (conceptual disorganization, hallucinations, and unusual thought content). Scores obtained from the BPRS rating range from 18 to 126. A higher total score represents more severe psychotic symptoms experienced by the participants.

The Positive and Negative Syndrome Scale for Schizophrenia (PANSS): developed by Stanley R. Kay, was used to assess positive and negative symptoms as well as general psychopathology and to measure the levels of these symptoms in case of schizophrenia or any other psychotic disorder (Brain et al., 2014). The scale has been translated into Chinese and has good validity and inter-rater reliability (Si et al., 2004).

The scale consists of 30 items rated from 0 (absent) to 7 (extreme) that represent increasing levels of psychopathology. Seven items are related to positive symptom subscale, seven items are related to negative symptom subscale, and the remaining 16 items are related to

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