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Experienced stigma and self-stigma in Chinese patients with schizophrenia

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ABSTRACT

Objective: To investigate experienced stigma and self-stigma in patients with schizophrenia in mainland China.
Methods: Ninety-five patients with schizophrenia, enrolled between January 2011 and March 2011, completed Chinese versions of two self-report questionnaires: the Internalized Stigma of Mental Illness (ISMI) scale and the Modified Consumer Experiences of Stigma Questionnaire (MCESQ). They also completed two other self-report questionnaires: the Social Support Rating Scale (SSRS) and the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire. Patients were also assessed by a senior psychiatrist using the Scale for Assessment of Positive Symptoms (SAPS) and the Scale for Assessment of Negative Symptoms (SANS).
All analyses were performed using SPSS 17.0 and included descriptive statistics, correlation analysis and multiple linear regression.
Results: On the ISMI, the percentage of participants who rated themselves above the mid-point of 2.5 (meaning high level of self-stigma) on subscales and overall score was 44.2% ($n=42$) for alienation, 14.7% ($n=14$) for stereotype endorsement, 25.3% ($n=24$) for perceived discrimination, 32.6% ($n=31$) for social withdrawal and 20.0% ($n=19$) on the overall score. On the MCESQ, the percentage of participants who rated themselves above the mid-point of 3.0 on subscales and overall score was 24.2% ($n=23$) for stigma, 1.1% ($n=1$) for discrimination and 1.1% ($n=1$) on the overall score. Some socioeconomic variables, but not positive or negative symptoms, were related to the severity of psychiatric stigma.
Conclusions: Results document the seriousness of experienced stigma and self-stigma in persons with schizophrenia. Strategies are needed to improve how governments and persons with schizophrenia cope with stigma.

1. Introduction

Many factors influence stigma in patients with mental disorders, and cultural context plays an essential role in its formation. Deeply held cultural and philosophical beliefs can promote stigma and act as a barrier to rehabilitation and recovery. In China, traditional cultural values, such as Confucianism, Taoism and Buddhism, strongly influence patients' and society's understanding and interpretation of mental illness and associated stigma. The core virtue in Confucianism, which has shaped Chinese culture for over 2000 years, is filial piety [1]. Filial piety encourages individuals to show respect for their elders and ancestors and to act in an ethical way, in harmony with the self, family, society and the universe. The extreme importance of social harmony and its maintenance take precedence over the expression of one's own opinions and values [2]. People are seen as living first and foremost in a strict network of social interaction (or *guanxi*). The maintenance of *guanxi* is dependent on the reciprocal returning of favors [3] which is itself directly related to the concept of "face" (or *mianzi*). Face is a crucial aspect of social identity and represents power and standing in Chinese social hierarchy. Thus, preserving face or *mianzi* is a part of daily life. Diagnosis of schizophrenia results in a "loss of face" for the individual [4], and suffering from mental illness is equated with extreme shame in Chinese society.

A review of the literature around the social and cultural history of medicine [5,6] reveals that psychiatric stigma has existed in Europe since the times of Ancient Greece and the Middle Ages. Such stigma continues to be prevalent in Western countries [7]. Psychiatric stigma not only leads to negative stereotyping and to discriminatory behavior towards those affected by mental illness [8,9], but causes feelings of shame in patients, both of which result in decreased life satisfaction and self-esteem [10]. Rehabilitation in schizophrenia patients is often hampered by stigma-related difficulties [11]. Stigma refers to the experience of discrimination by patients and the resulting limited social participation [12]. Self-stigma mainly refers to the internalization of public stigma. Corrigan [13] defines self-stigma as the internalizing of shame, blame, hopelessness, guilt and fear of discrimination associated with

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mental illness. It has also been described as a process, wherein the patient alters both what they expect of themselves and how they expect to be treated by society [14].

It is very common for those with mental illnesses to experience discrimination, as reported in findings in Hong Kong [15,16], Mainland China [17,18], as well as in the Western literature [9,19]. However, the extent and nature of stigma and self-stigma in schizophrenia patients in China are still largely understudied. In particular, previous research has used nonstandardized questionnaires, making between-study comparisons difficult. For these reasons, our study measured stigma in a Chinese setting using two standardized questionnaires and describes the characteristics of stigma, self-stigma and other relevant factors. We discuss recommendations for policy around stigma prevention, especially related to patients' reintegration into society.

2. Methods

2.1. Participants

A nonprobabilistic sampling method was used to recruit participants. The participants were inpatients or outpatients with schizophrenia receiving treatment in the Second Xiangya Hospital between January and March 2011. For inclusion, the patients had to be (1) diagnosed with schizophrenia. Patient assessments were done by a psychiatrist using the *DSM-IV* criteria (American Psychiatric Association, 1994), and diagnoses were independently confirmed by a psychologist in a structured clinical interview (Mini-International Neuropsychiatric Interview); (2) aged between 17 and 60; (3) not drug or alcohol dependent; (4) able to understand the questionnaires. Patients with organic brain syndrome or mental retardation were excluded.

Patients who did not complete the questionnaires or refused participation were excluded. The survey was conducted between January, 2011, and March, 2011.

All subjects and their guardians gave written consent to participate in the study. Ethical approval for this study was obtained from the Research Ethics Committee of the Second Xiangya Hospital at the Central South University.

2.2. Methods

2.2.1. Demographic data

A questionnaire, designed by the authors, was used to collect basic demographic data as well as information on the patient's symptoms and included age, gender, level of education, age of onset, duration of illness, frequency of hospitalization, family history, employment status and relationship status.

2.2.2. Stigma

2.2.2.1. Self-stigma. Self-stigma was assessed using the Internalized Stigma of Mental Illness Inventory scale (ISMI) [20]. This scale contains 29 items, scored on four-point Likert scales (1 = *strongly disagree* to 4 = *strongly agree*) and grouped into five subscales: alienation (patient's experience of limited participation in society), stereotype endorsement (tendency to agree with common stereotypes about people with mental illness), perceived discrimination (experience of unfair treatment by others), social withdrawal (actively avoiding social interaction) and stigma resistance (ability to deflect or resist stigma). Based on previous work in the field [21,22], we combined the first four subscales (i.e., excluding stigma resistance) to calculate an overall stigma score (higher scores suggesting more severe experiences of stigma). Good internal consistency, factorial and convergent validity, and test-retest reliability have been reported previously [20,23]. In our study, the internal consistency of the 24-item ISMI was $\alpha = .826$.

2.2.2.2. Experience of stigma. Experience of stigma was measured using the Modified Consumer Experiences of Stigma Questionnaire (MCESQ), which has two sections covering stigma and discrimination experiences. The original version (CESQ) was developed by Wahl [9] in 1999 and modified by Dickerson et al. [7] in 2002 replacing the term "consumers" with "persons with mental illness," "persons who have a psychiatric disorder" and "persons who use psychiatric services" as appropriate [7]. The instrument consists of 19 items, scored on five-point Likert scales and grouped into two subscales: stigma experiences and discrimination experiences. The former represents interpersonal experiences of dealing with others' negative attitudes toward their mental illness. The latter measures patients' experiences of discrimination in various parts of life, including employment, housing and pursuing volunteer activities. This questionnaire has been used in Western countries and has been shown to have good reliability and validity [23]. In our study, the internal consistency of the MCESQ was $\alpha = .635$.

2.2.3. Social support

Social support was measured using the Social Support Rating Scale (SSRS) developed by Xiao [24]. This instrument measures the social support received by participants and consists of 10 items grouped into three subscales: objective support, subjective support and support availability. Items were mostly scored on four-point Likert scales (excluding questions asking for total number of "sources of support"). The internal consistency of the SSRS was $\alpha = .614$.

2.2.4. Quality of life

Quality of life was measured using the World Health Organization Quality Of Life questionnaire (WHOQOL-BREF). The WHOQOL-BREF is a shorter version of the WHOQOL-100 instrument (developed for cross-cultural validity and includes 100 items) and contains a total of 26 items, scored on five-point Likert scales and grouped into four domains: physical health, psychological health, social relationships and environment. Various studies have reported high validity and reliability [25]. In our study, the internal consistency of the WHOQOL-BREF was $\alpha = .903$.

2.2.5. Severity of psychotic symptoms

Chinese versions of the Scale for the Assessment of Negative Symptoms (SANS) and the Scale for the Assessment of Positive Symptoms (SAPS) [26,27] were used for the assessment of negative and positive schizophrenia symptoms. The SANS and SAPS consist of 24 and 34 items, respectively, scored on six-point Likert scales (from 0 = *not present* to 5 = *severe*). The SANS contains five subscales: affective blunting, alogia (impoverished thinking), avolition/apathy, anhedonia/asociality and attention. The SAPS has four subscales: hallucinations, delusions, bizarre behavior and positive formal thought disorder. Scores measure severity of negative and positive symptoms. The Chinese versions of the two scales have good reliability and validity [28].

2.3. Analytic strategy

All statistical analyses were performed using SPSS version 17.0 for Windows.

Statistical analyses included descriptive statistics, correlation analysis and multiple linear regression.

The ISMI is scored on a four-point Likert scale with possible scores ranging from 1 to 4, and higher scores indicate higher levels of a particular attribute. Previous research has defined a high level of self-stigma as an average score above the midpoint of 2.5 [20,29]. Other studies have reported ISMI scores as follows: minimal stigma <2, low