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ORIGINAL PAPER

An integrative model of internalized stigma and recovery-related outcomes among people diagnosed with schizophrenia in rural China

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Abstract

Purpose Internalized stigma, an adverse psychological process, severely impedes the lives of people diagnosed with schizophrenia and restricts them from social integration and recovery. The aim of this study was to empirically evaluate an integrative model of relationship between internalized stigma and patients' recovery-related outcomes among people diagnosed with schizophrenia in a rural Chinese community.

Method A total of 232 people diagnosed with schizophrenia in Xinjin, Chengdu, participated in this study and completed measures of internalized stigma, social interaction, perceived social support, social functioning, and symptoms. The internalized stigma of mental illness scale (ISMI) was used to measure the internalized stigma. Path analysis was used to test the association between internalized stigma and recovery-related outcomes.

Results There were no significant differences in mean scores of ISMI by gender, age (18–64 years and ≥ 65 years), education, marital status, or economic capacity. Internalized stigma was negatively associated with perceived social support and social interaction. Furthermore, higher level of internalized stigma was associated with impaired social functioning, and a lower level of social functioning was significantly associated with more severe symptoms.

Conclusion Internalized stigma is associated with poor social interaction and weakened perceived social support in people diagnosed with schizophrenia, and is linked negatively to outcomes in their recovery. It is essential to tailor interventions related to reducing internalized stigma within a Chinese context and evaluate the effectiveness of anti-stigma intervention on recovery for people diagnosed with schizophrenia.

Keywords Internalized stigma · People diagnosed with schizophrenia · Recovery · Rural China

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Introduction

Internalized stigma attached to mental health, also known as self-stigma, signals an adverse psychological process by which people with mental illness endorse the public's stigmatizing attitudes, which is then internalized as their own beliefs (e.g., self as dangerous, self as unpredictable, and self as incompetent), leading to low self-esteem and high self-devaluation [1, 2]. Numerous studies have found internalized stigma to be common [3–5], with between 21.7% and 49.5% among people with mental illness worldwide experiencing moderate or high levels of internalized stigma [6, 7].

Schizophrenia, a severe mental illness affecting approximately 1% of the population worldwide, has been seen as a lifelong illness with little hope of recovery [8]. A growing body of empirical research has emerged examining

internalized stigma and its deleterious effect upon people with a diagnosis of schizophrenia [9]. Most of these studies have found that internalized stigma is correlated with a number of negative consequences, including diminished self-esteem [10, 11], hopelessness and jeopardized quality of life [12], weakened social support network and reduced social interaction [13], a reluctance to seek professional service [14, 15], poor treatment compliance [16, 17], impaired social functioning [18], and more severe psychiatric symptoms [19]. Given the adverse psychosocial and psychiatric outcomes reported in previous studies on internalized stigma among people with mental illness [20, 21], it is reasonable to suggest that internalized stigma is one of the biggest obstacles to recovery from severe mental illness (e.g., schizophrenia).

Yanos and his colleagues [22] offer a conceptual model for understanding how internalized stigma might influence both subjective and objective outcomes related to recovery. The model posits that internalized stigma damages hope and self-esteem, which in turn, weakens social interaction, increases depression, and heightens the risk of suicide. Moreover, the model hypothesizes that vocational functioning and symptom severity are also associated with internalized stigma. Yanos et al. provide empirical evidence related to the proposed model, demonstrating that internalized stigma is associated with self-esteem and quality of life [12, 23]. Specifically, path analysis results indicated that internalized stigma affects hope and self-esteem, and leads to negative outcomes related to recovery, including coping strategies and symptom severity [24].

Similarly, according to modified labelling theory proposed by Link et al. [25], concurring with devalued views of other people might bring about low self-esteem, poor functioning, and weak social support among those with mental illness. As a result of these negative outcomes, internalized stigma is a factor predicting relapse among those whose psychiatric symptoms have stabilized. Several previous studies based on modified labelling theory have pointed out that social support plays a significant role in mental health recovery, which is negatively associated with internalized stigma [26]. Another study indicated that high levels of internalized stigma are associated with low levels of social functioning and increased symptom severity [27].

Although the studies aforementioned have examined the relationship between internalized stigma and its negative outcomes, only a few studies have tested both psychosocial and psychiatric outcomes that are related to recovery. Specifically, there is no prior research that simultaneously tests the effects of internalized stigma on social support and symptom severity within one model. Moreover, most studies of internalized stigma and its effects were conducted in Western countries [27, 28]. This is despite the fact that there is growing evidence indicating high levels of internalized stigma among people with severe mental illness in China and that internalized stigma is associated with weak social support and poor quality of life [29]. Social support is an important mediator between internalized stigma and recovery, particularly considering the collectivist nature of Chinese cultural mores and values. As epitomized in Confucian ethics, which adopt the principle of giving priority to groups over individuals, maintaining strong social interaction with and perceiving strong support from network members are critical for promoting recovery for people with severe mental illness [30].

In this study, we integrated Yanos et al.'s path model of internalized stigma [12, 25] with Link et al.'s modified labelling theory with the goal of testing the association between internalized stigma, psychosocial outcomes (perceived social support and social interaction), and psychiatric outcomes (social functioning and symptom severity), as they relate to recovery among people diagnosed with schizophrenia. Specifically, we tested the following hypotheses: (1) patients' internalized stigma is directly and negatively related to perceived social support and social interaction; (2) lack of perceived social support and decreased social interaction are associated with poorer social functioning and greater severity of psychiatric symptoms, respectively; and (3) poorer social functioning is associated with greater severity of symptoms.

Methods

Research setting and participants

The study data were derived from the Chengdu Mental Health Project (CMHP), a prospective longitudinal follow-up study on mental illness and mental health services in Chengdu, China, [31, 32]. All subjects with schizophrenia ($n = 232$) were identified from an epidemiological investigation of 152,776 people aged 15 years and older in six townships of Xinjin County in 2015 [33]. The research methodology of this epidemiological investigation has been detailed in other publications [34, 35]. Subjects were identified through screening procedures for psychosis (face-to-face interviews with the head of each household together with key informant) and general psychiatric interview. Inclusion criteria for the sample in this study were the following: (1) meet the International Classification of Diseases Tenth Revision (ICD-10) criteria for a diagnosis of schizophrenia, and (2) voluntarily complete the Internalized Stigma of Mental Illness (ISMI) Scale. All participants self-completed measurements of internalized stigma, perceived social support and social interaction; for those with low literacy level, the interviewers read the questionnaires. In terms of social functioning and symptom severity, each of the instruments was

administered by trained psychiatrists. Ethical approval for the study was obtained from the ethics committee at the University of Hong Kong, and all research participants received informed consent including a detailed explanation of the study.

Measures

The Internalized Stigma of Mental Illness scale (ISMI) is a 24-item self-report scale designed to assess an individual's subjective experience of stigma related to mental illness, which includes four subscales: (1) alienation domain (6 items) measures the participants' experience of internalizing a "spoiled identity" because of mental illness, such as *"I feel inferior to others who don't have a mental illness"*, (2) stereotype endorsement domain (7 items) measures the degree to which participants agree with common belief about people with mental illness, such as *"People with mental illness cannot live a good, rewarding life"*, (3) social withdrawal domain (6 items) measures participants' behaviors of avoiding people and activities, such as *"I don't socialize as much as I used to because my mental illness might make me look or behave "weird"*, and (4) discrimination experience domain (5 items) examines participants' perception of discrimination from others, such as *"People ignore me or take me less seriously just because I have a mental illness"*. Each item is rated on a four-point Likert scale anchored at 1 = strongly disagree and 4 = strongly agree. Higher total scores are indicative of higher levels of internalized stigma [36]. Favorable psychometric properties, including internal consistency ($\alpha = 0.90$) and test–retest reliability ($r = 0.92$), have been documented in prior studies [37, 38]. The ISMI was translated into Chinese with good psychometric properties, including high internal consistency reliability and good construct validity [11, 29, 39]. In our study, we observed a high level of internal consistency for ISMI ($\alpha = 0.89$) [40].

The Duke Social Support Index (DSSI) is a 23-item instrument that measures an individual's objective and subjective social support [41]. There are three subscales, including social interaction (4 items), perception of social support (7 items) and instrumental social support (12 items). For this study, we used the subscales of social interaction and perception of social support. These two subscales are answered on a three-point Likert format, and a higher score indicates more social interaction and more perceived social support. The DSSI has proven to reach an acceptable level of internal consistency reliability among people with mental illness in a Chinese rural area [42]. The subscales of social interaction ($\alpha = 0.76$) and perception of social support ($\alpha = 0.92$) have demonstrated good internal consistency.

The Global Assessment of Functioning (GAF) was used to examine the overall level of functioning of people with mental illness [43]. The total score of GAF is from 0 to 100, in which a higher score means better social functioning. GAF has been widely used in people diagnosed with severe mental illness [32].

The Positive and Negative Syndrome Scale (PANSS), a 30-item rating scale including three subscales: positive, negative, and general psychopathology, was used to examine symptom severity [44, 45]. The PANSS was completed by trained psychiatrists after an interview with participants. The PANSS has proven to reach an acceptable level of reliability [31, 46].

Demographic and clinical characteristics, including gender, age, marital status, education, and economic capacity, were collected through the patients' investigation by trained psychiatrists. For all subjects in our research, at least one person who was familiar with the subject's life and circumstances as well as the subjects themselves, were interviewed.

Statistical analysis

SPSS Windows software (version 23.0) and Mplus statistical software (version 7.0) were used for data analysis. Demographic data were summarized by descriptive statistics. All the variables included in the study were summarized using percentages (categorical variables), and means and standard deviations (continuous variables). We used F test and t test to examine the relationships between internalized stigma, demographic and clinical characteristics. The correlation matrix between internalized stigma, social interaction, perceived social support, social functioning and symptom severity was presented. Path analysis was used to test the proposed model between internalized stigma and recovery-related outcomes. The goodness-of-fit of the model was assessed with multiple fit statistics, including chi-square test, comparative fit index (CFI), and the root mean square error of approximation (RMSEA). In this study, we operated a method of linear interpolation to deal with the missing data.

Results

Demographic and clinical characteristics

The means and standard deviation of the test scores of demographic and clinical characteristics are summarized in Table 1. An overwhelming (90.5%) of the participants had not received a high school education, that is, grade 9 or above, and almost half of the participants did not have any income (53.4%). There were no significant differences in mean scores of ISMI by gender, age (18–64 years and ≥ 65 years), education, marital status, or economic capacity.

Table 1 Demographic characteristics of people with schizophrenia

Characteristics	*N*	%	ISMI score			
			M	SD	Test statistic	*P*
Gender					$t=-0.068$	0.95
Male	95	40.9	2.46	0.32		
Female	137	59.1	2.46	0.27		
Age (years)					$t=1.39$	0.17
18–64	176	75.8	2.48	0.30		
≥65	56	24.1	2.42	0.26		
Marital status					$t=-0.21$	0.83
Never married	35	15.1	2.45	0.25		
Married (current or previous)	179	77.2	2.47	0.30		
Education (years)					$t=-0.46$	0.64
≤9	210	90.5	2.46	0.29		
>9	22	9.4	2.49	0.26		
Economic capacity					$F=0.68$	0.41
Major earner in family	20	8.6	2.45	0.37		
Partly earner in family	88	37.9	2.44	0.27		
No income	124	53.4	2.48	0.29		

Relationship between the variables

A correlation matrix of all the variables (internalized stigma, social interaction, perceived social support, social functioning, and symptom severity) included in path analysis is illustrated in Table 2. Internalized stigma had a significant negative association with social interaction ($r=-0.19$, $p<0.01$), perceived social support ($r=-0.12$, $p<0.05$) and social functioning ($r=-0.19$, $p<0.01$). Furthermore, there was a significant positive correlation between internalized stigma and symptom severity ($r=0.19$, $p<0.01$).

The path model

Figure 1 presents the results of path analysis for testing our model of internalized stigma and outcomes related to recovery. The model fit indices ($\chi^2=0.99$, $df=1$, $p=0.3198$; CFI = 0.96; RMSEA = 0.072) were good, suggesting that the observed data fitted well with the proposed model.

As hypothesized, the results showed that internalized stigma was significantly associated with perceived social support and social interaction, indicating that participants who had endorsed a higher level of internalized stigma tended to have poor perceived social support and a lower level of social interaction. Weakened perceived social support was related to reduced social interaction. Higher level of internalized stigma was associated with impaired social functioning, in that participants who reported a higher level of internalized stigma tended to have poorer social functioning. The results also supported that a lower level of social functioning was significantly associated with more severe symptom. In addition, social interaction was negatively related to symptom severity. However, perceived social support was not significantly associated with symptom severity.

Discussion

The current study explored associations between internalized stigma and several outcomes related to recovery. The findings of this study suggest that internalized stigma has negative associations with social interaction, perceived social support, social functioning and symptom severity in people diagnosed with schizophrenia. This was the first study conducted in a Chinese rural community to examine internalized stigma and recovery-related psychosocial and psychiatric outcomes using path analysis, providing evidence on an integrated model of internalized stigma and recovery-related outcomes.

Internalized stigma was not associated with any of the five demographic characteristics included in this study. The absence of significant association is not a surprising result given the lack of consistent findings in prior research on the role of demographic characteristics as covariates of internalized stigma. For example, while a few studies found women and younger people to report higher levels of internalized stigma than men and older people [19, 47], other studies found no significant differences of internalized stigma among different age groups and between male and female [9, 28, 48]. Moreover, although several studies found that education was associated with internalized stigma [6, 38, 49], the lack significant association documented in the current study may be attributed to the lack of variability in the

Table 2 Correlations among variables included in path analysis

Variables	1	2	3	4	5	6	7	8	9	10	11	12
1. ISMI_total scale	1											
2. ISMI_alienation	0.82^{***}	1										
3. ISMI_stereotype endorsement	0.83^{***}	0.63^{***}	1									
4. ISMI_discrimination experience	0.82^{***}	0.63^{***}	0.59^{***}	1								
5. ISMI_social withdrawal	0.86^{***}	0.66^{**}	0.66^{***}	0.65^{***}	1							
6. Social Interaction	-0.19^{**}	-0.17^{**}	-0.22^{**}	-0.16^{*}	-0.20^{**}	1						
7. Perceived Social Support	-0.12^{*}	-0.11	-0.22^{**}	-0.12	-0.17^{**}	0.44^{***}	1					
8. Social Functioning	-0.19^{**}	-0.07	-0.22^{**}	-0.28^{***}	-0.20^{**}	0.37^{***}	0.46^{***}	1				
9. PANNS_total scale	0.19^{**}	0.09	0.22^{**}	0.25^{***}	0.20^{**}	-0.41^{***}	-0.43^{***}	-0.65^{***}	1			
10. PANNS_positive	0.09	0.03	0.17^{*}	0.13^{*}	0.07	-0.19^{**}	-0.30^{***}	-0.43^{***}	0.72^{***}	1		
11. PANNS_negative	0.13^{*}	0.06	0.12	0.21^{**}	0.18^{**}	-0.45^{***}	-0.39^{***}	-0.54^{***}	0.78^{***}	0.24^{***}	1	
12. PANNS_general psychopathology	0.22^{**}	0.12	0.25^{***}	0.25^{***}	0.23^{**}	-0.34^{***}	-0.35^{***}	-0.60^{***}	0.93^{***}	0.60^{***}	0.63^{***}	1

ISMI Internalized stigma of mental illness, *PANNS* Positive and Negative Syndrome Scale

$^{***}p<0.001$; $^{**}p<0.01$; $^{*}p<0.05$

educational background of the study participants. Recall that less than 10 % attained some high school education or above in the study sample (Table 1). By the same token, economic capacity was not linked to internalized stigma, possibly due to the prevailingly lower income level of people diagnosed with schizophrenia in rural China, regardless of their status as earner or non-earner in the family.

Path analysis results are largely congruent with the three study hypotheses derived from the integrative model. Consistent with prior research, there is significant association among internalized stigma, perceived social support and social interaction [24, 26]. Higher levels of internalized stigma were linked to lower levels of perceived social support, as well as lower levels of social interaction. Social support has shown to be a protective factor buffering against internalized stigma in Western countries [50]. It is reasonable to assume that people who feel themselves to be less stigmatized are more inclined to reach out to their social network members, which in turn allows them to receive assistance from others and gain a sense of being valued [25]. Our finding of a direct and negative association between internalized stigma and perceived social support, and between internalized stigma and social interaction is particularly relevant to Chinese rural communities because extended kinship networks are often located in the same village or township, providing an essential source of support and help to facilitate the recovery for persons diagnosed with schizophrenia.

Studies have shown that people diagnosed with severe mental illness who experience more internalized stigma often harbor a sense of being less worthy of life goal achievement, such as obtaining a job, thereby interfering with social functioning of the individual [51]. In partial support for our second hypothesis, lack of perceived social support and decreased social interaction were both associated with impaired social functioning. This finding gives credence to the notion that social withdrawal, an important component of internalized stigma, poses as a barrier in undermining mental health recovery. People diagnosed with schizophrenia who endorse a high level of internalized stigma may avoid social connection with family and kin, and reduce engagement in activities in their village and township, which can adversely affect long-term social functioning.

Interestingly, social interaction, but not perceived social support, was negatively associated with severity of psychiatric symptoms in this study. This finding suggests that actual connection with others may be a more important factor than subjective perception of support from others with regard to symptom reduction, an indicator of recovery. In rural Chinese communities, social interaction is based on more strictly defined networks composing primarily of immediate family and kin, when compared to urban communities. Social interaction is further governed by cultural

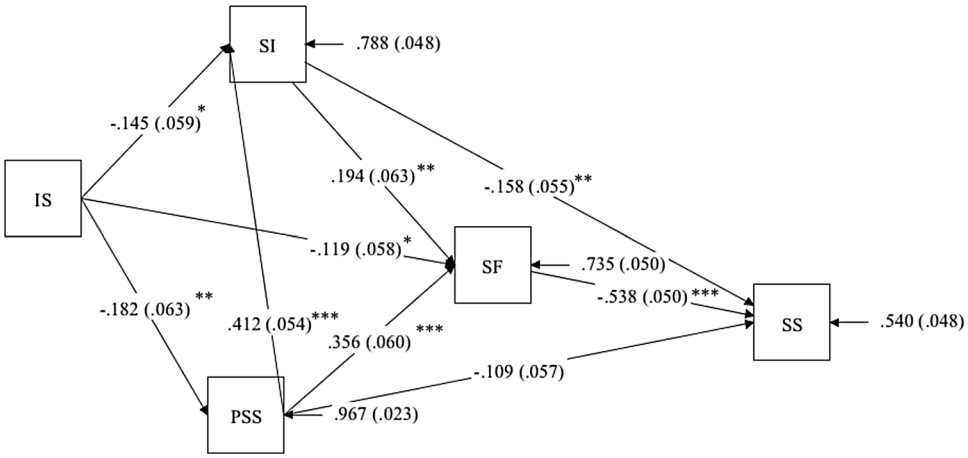

Fig. 1 Path model of Internalized stigma and recovery-related outcomes. *IS* Internalized stigma, *PSS* perceived social support, *SI* social interaction, *SF* social functioning, *SS* symptom severity; $*p<0.05$; $**p<0.01$; $***p<0.001$

mores about social exchange, that is, reciprocation of favors is expected among network members [52]. Meanwhile, 'face concern' is a vital cultural value in Chinese societies as well, and Chinese people often desire to promote their social status through interaction with community leaders and other people with high social status in the community [53]. A diagnosis of schizophrenia, considered to be the most stigmatizing disease in Chinese society, inevitably results in 'loss of face' among family and kin. Therefore, people diagnosed with schizophrenia, regardless of the extent of subjective support experienced, may be shunned by their network members in daily social interaction. This reinforces a sense of isolation and abandonment on the part of the patient, which is not conducive to reduction of psychiatric symptoms [54]. Given our finding confirming the negative relationship between social interaction and symptomatology, further efforts are necessary to examine the mechanism through which social interaction can be facilitated between patients and their network members in the cultural milieu of rural China.

Finally, our path analysis results indicated that lower levels of social functioning are associated with more severe mental illness symptoms, lending support for the third hypothesis. Overall, the relationships among internalized stigma, psychosocial outcomes and psychiatric outcomes are largely consistent with the integrative model we proposed based on the work of Yanos et al. [21] and Link et al. [24]. The results of this study contribute to the understanding of the relationships between internalized stigma and recovery-related outcomes, and are in line with previous research indicating that internalized stigma is a formidable barrier in the process of recovery.

Our findings signal the need for policymakers, administrators and researchers in the mental health field to design stigma reduction programs to combat discrimination, improve quality of life, and facilitate recovery for people diagnosed with schizophrenia in rural China. Given the potential role of social support as a mediator between internalized stigma and psychiatric outcomes, it is also important to understand the mechanism upon which internalized stigma affects social support, as well as how reduced social support is associated with indicators of psychiatric recovery. Increasing the size of a person's social network to enable more frequent and meaningful interaction might help to buffer the negative effect of internalized stigma [26]. Yang and Kleinman propose "restoring face" as a means unique to Chinese culture that may challenge internalized stigma [54]. How to restore one's spoiled identity in a rural context in which social relationships are restricted within a village or township with low level of residential mobility deserves further research. Given the centrality of work in Chinese culture, one proposal has been to enhance an individual's ability to re-engage in their original social exchange network via providing vocational support [53]. In addition to the role of psychosocial beliefs in reducing internalized stigma, biomedical explanations could not be ignored. Read and his colleagues reviewed the literature and found that biogenetic causal beliefs and diagnostic labelling are positively associated with negative stereotype, and suggested that incorporating a multidisciplinary perspective in stigma reduction programs could seek a range of alternatives to the biogenetic explanations of mental illness [55].

There are limitations to this study that should be mentioned. First, this study adopts a cross-sectional design and cannot test cause–effect relationships. Further research using a longitudinal cohort design is necessary to examine the effects of internalized stigma on recovery-related outcomes. In terms of measurements, this study did not use a standardized recovery scale as the outcome variable. Instead, we included four proxy measures to assess the psychosocial and psychiatric aspects of recovery. Future research should consider using a standardized measurement of recovery, which must be adapted to the rural Chinese setting. In addition, the standardized scale used for measuring internalized

stigma does not include a biogenetic perspective, which may be relevant to Chinese traditional beliefs. In the future, biogenetic causal beliefs and diagnostic labelling should be considered in evaluating internalized stigma. Finally, there are other variables not included in this study that may play a significant role in understanding internalized stigma, such as self-esteem, and these variables need to be examined further.

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Author contributions Dr. Ran designed the study and Miss. Zhang wrote the first draft. The draft was modified by Dr. Wong, Dr. Ran, Mrs. Yu, Dr. Ni, Prof. He, Prof. Chan. and Prof. Bacon-Shone. In addition, Dr. Gong, Dr. Huang, Ms. Hu, Ms. Tang, and Dr. Cao made contribution to the data collection. The data were derived from Dr. Ran's Chengdu Mental Health Project (CMHP). All authors made a significant intellectual contribution to the paper.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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