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Validation of the Malayalam version of the Internalized Stigma of Mental Illness (ISMI) scale

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ABSTRACT

Little is known about internalized stigma of mental illness in India. A reason for this could be the lack of valid assessment instruments adapted for the diverse cultures and languages of the country. One of the most widely used and accepted questionnaires to assess internalized stigma is the 29-item Internalized Stigma of Mental Illness (ISMI) scale. The aim of the present study was to translate and adapt the ISMI to the Malayalam-speaking population of Kerala, India and to assess its content and factorial validity. The content validity of the Malayalam-language ISMI was studied through interviews with 7 experts on stigma in India. Factorial validity was examined by means of a confirmatory factor analysis (CFA) based on a cross-sectional survey among 290 patients with mental illness attending follow-up outpatient and primary care clinics in Kerala, India. The expert panel concluded that the items of the translated questionnaire adequately represent internalized stigma in the Malayalam-speaking population of Kerala. The theorized factor structure of the ISMI consisting of five factors showed a suboptimal model fit (WRMR = 0.940; TLI = 0.971, CFI = 0.948; RMSEA = 0.059) which improved considerably after removal of the stigma resistance factor and three items with poor factor loadings (WRMR = 0.819; TLI = 0.982, CFI = 0.966; RMSEA = 0.051). Although our study identifies some sources of model ill-fit, it shows that a reduced version of the Malayalam-language ISMI can be a valuable tool for the study of internalized stigma in this cultural setting.

1. Introduction

Stigma of mental illness manifests in the form of public stigma and personal stigma. Public stigma is the reaction that people show towards those with mental illness. Personal stigma can be perceived stigma (society's feelings about the stigmatized group), experienced stigma (individual experience of discrimination) or internalized stigma (internalization of public stigma resulting in self-stigmatization) (Corrigan and Watson, 2002).

Internalized stigma, also referred to as self-stigma, is the "*the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself*" (Ritsher et al., 2003, p. 32). Internalization of stigma occurs in three steps: the individual slowly accumulates the public stereotypes towards mental illness *(stereotype awareness)*, gradually loses his/her reality and agrees with society's beliefs *(stereotype agreement)*, and changes his/her behavior accordingly *(stereotype concurrence)* (Watson et al., 2007). Psychosocial factors such as hope and social support have been found across multiple studies to have a consistent and negative correlation with internalized stigma, whereas socio-demographic factors have not been associated consistently (Livingston and Boyd, 2010). Internalized stigma can have negative effects on adherence, self-efficacy, quality of life and personal life by preventing people with mental illness from enjoying their basic rights and needs, leading to problems in finding a job or causing marital disruptions (Watson et al., 2007; Corrigan et al., 2006, 2013). Internalized stigma is also a barrier for mentally ill patients to avail treatment early. As a result, the recovery period of patients may be prolonged and they may experience complications and face serious financial difficulties (Boyd et al., 2010).

The internalized stigma of mental illness has been studied using various methods (Link et al., 1997) and there are a number of quantitative questionnaires available measuring the internalized stigma among people with mental illness (Livingston and Boyd,

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2010; Brohan et al., 2010). One of the most commonly applied questionnaires is the 29-item Internalized Stigma of Mental Illness (ISMI) scale developed by Boyd (formerly Ritsher) and colleagues (Ritsher et al., 2003). The ISMI measures the subjective experiences of stigma and can be applied to people with various mental disorders. The ISMI has been translated in over 50 languages and has been found to be valid and reliable in different cultural settings (Boyd et al., 2014). It consists of five domains (sub-scales): alienation, stereotype endorsement, discrimination experience, social withdrawal, and stigma resistance. The *alienation* domain (six items) measures the subjective experience of being less than a full member of society. The *stereotype endorsement* domain (seven items) captures the extent to which participants agree with stereotypes about people with mental illness. The *discrimination experience* domain (five items) assesses participants' perception of how they are discriminated against. The *social withdrawal* domain (six items) aims to measure the extent to which individuals try to isolate themselves due to stigma. The *stigma resistance* domain measures the degree to which individuals can lead a happy life despite their experience of stigma. Each item of the ISMI provides a four-point Likert response format comprising the response options ''strongly disagree'', ''disagree'', ''agree'' and ''strongly agree''.

While many studies have been conducted on different aspect of mental illness in India, studies examining perceived and experienced stigma of patients in India are usually qualitative or limited to certain conditions such as schizophrenia (Loganathan and Murthy, 2008; Thara and Srinivasan, 2000). As far as we know, no quantitative assessment of internalized stigma of mental illness, including its prevalence and determinants, has been conducted in India. One reason for this might be that validated instruments for the assessment of internalized stigma among speakers of the different languages in that country are scarce. To the best of our knowledge, aside from Tamil and Bengali only an ISMI version for the Hindi-speaking population of India is available (Boyd et al., 2014). However, large proportions of the Indian population, particularly in Southern states such as Kerala, have little proficiency of Hindi and other languages, which is why the questionnaire cannot be applied there. With its population of 33.3 million mainly Malayalam-speaking people, Kerala is a state in the forefront of epidemiological transition (i.e., the transition from communicable to non-communicable disease including mental illness) in India and, in comparison to the other Indian states, has the largest proportion of those with several major risk factors for chronic diseases, including mental disorders (Thankappan et al., 2010). In 2008, Kerala recorded the fourth highest suicide rate in India (25.2 per 100,000 of the population), two and a half times the national average. Depression as well as risk factors for mental conditions such as divorce, family and marriage breakdowns and demographic ageing are also very prevalent in Kerala (Bary, 2008). Studying internalized stigma in this context is very important as stigma is one of the factors that may lead to delays in seeking appropriate treatment for mental health conditions. For this purpose, a validated assessment tool is necessary. The aim of our present study was to make the ISMI applicable to this population by translating and adapting the questionnaire to the cultural setting of Kerala, India, and assessing both its content and factorial validity.

2. Methods

2.1. Translation and adaptation of the Internalized Stigma of Mental Illness (ISMI) scale

The original ISMI was translated and adapted for the population of Kerala, India following published guidelines (Beaton et al., 2000). For this purpose, it was translated from English to Malayalam using forward and backward translation. The backward translation was reviewed by Dr. Jennifer Boyd, the developer of the original ISMI. Based on the evaluation of the backward translation, some nuances in the meaning of the Malayalam items were adjusted to better reflect the meaning of the original items. No items were added or subtracted for cultural reasons at this stage. The translated Malayalam-language ISMI (see Fig. 1; see Appendix for the original English language version) was pilot tested among 20 patients attending follow-up outpatient clinics in a community health centre and a primary health centre in Kerala. The pilot test did not identify any problems in the usability of the questionnaire.

2.2. Content validity

To examine the content validity of the Malayalam-language ISMI, the translated questionnaire was given to native speakers of Malayalam who are experts in the field of epidemiology ($n = 1$), stigma research ($n = 2$), psychiatry ($n = 2$) and clinical psychology ($n = 2$). The experts were asked to review the questionnaire and to evaluate whether the content of the scale is adequate to assess internalized stigma of mental illness among speakers of Malayalam in Kerala. They considered whether any questions should be added or subtracted.

2.3. Factorial validity

2.3.1. Study design and data collection

To examine the factorial validity of the Malayalam-language ISMI, a cross-sectional survey was conducted among 290 patients attending follow-up outpatient community-based or psychiatric hospital-based mental health clinics in Kerala, India. The study samples were collected from 13 randomly selected government health care centers where the District Mental Health Programme (DMHP) has integrated mental health into primary care and in follow-up outpatient clinics of a government Mental Health Centre (government psychiatric hospital) in the Trivandrum district of Kerala. The selected DMHP clinics include district hospitals ($n = 1$), *taluk* (administrative unit below district) headquarter hospitals ($n = 1$), regional health centers ($n = 1$), community health centers ($n = 5$), and primary health centers ($n = 5$). Only patients aged 18 years or above with a clinical diagnosis of mental illness who have had a mental illness for six months or more and who have resided in Trivandrum for more than six months were included in the study. Patients with hearing or speaking impairment were excluded.

The survey instrument comprised the translated Malayalam-language ISMI, information on socio-demographic characteristics and illness-related factors. The study was approved by the Institutional Ethical Committee of the Sree Chitra Tirunal Institute for Medical Sciences and Technology, as well as by the DMHP and MHC, Trivandrum, India. It was funded by means of own resources.

2.3.2. Statistical analysis

Arithmetic means and proportions were used for purposes of sample description. The descriptive analyses were conducted using R version 3.0.2 (The R Foundation for Statistical Computing, 2013).

Given the categorical nature of the ISMI items, means and variance adjusted weighted least squares (WLSMV) confirmatory factor analysis was conducted to examine the factor structure of the Malayalam ISMI (Byrne, 2012). Following established guidelines (Brown, 2006), the analysis of the factor structure of the ISMI began with the examination of the first-order model consisting of 29 items and the five factors ''alienation'' (items 1, 5, 8, 16, 17, 21), ''stereotype endorsement'' (items 2, 6, 10, 18, 19, 23, 29), ''discrimination experience'' (items 3, 15, 22, 25, 28), ''social