



Self-stigma in patients with schizophrenia: a multicentric study from three Latin-America countries

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Abstract

The aim of this study was to describe the degree of self-stigma in patients with schizophrenia across three Latin-Americans countries (Bolivia, Chile and Peru). The study included 253 outpatients that were assessed using the Internalized Stigma of Mental Illness Scale (ISMI). The results show that 48.7% of patients from Bolivia report high internalized stigma compared to 38.6% from Chile and 28.6% from Peru. There were no statistically significant differences in ISMI mean total scores for country ($p = 0.057$), however, there were significant differences on two subscales: alienation and social withdrawal for which Bolivia had the highest scores. In conclusion, even though these countries share several common cultural characteristics, there are also some differences between them on patients' self-stigma.

Keywords Schizophrenia · Self-stigma · Latin-America

Introduction

There has been an increase in research on self-stigma among persons with severe mental illness over the past 2 decades and the findings of several studies have shown that this stigma is a neglected but vitally important issue in the course of illness of these patients [1–5]. Self-stigmatizing beliefs emerge when patients endorse and internalize the prejudices

and the negative stereotypes associated with having severe mental health illness [6, 7].

The findings of a systematic review by Gerlinger and colleagues [8] indicate that from one-third to one-half of patients with schizophrenia feel shame as a consequence of the disorder [3]. Moreover, this internalized stigma has a wide range of adverse effects, including: profound psychological adversity, perceptions of devaluation, stress, lower quality of life, hopelessness, self-esteem, and self-efficacy.

These effects have consequences such as, impaired social adaptation, limited social support, unemployed, income loss, reduced adherence to the treatment of psychiatric disorders and treatment effectiveness, all of which indicates that self-stigma is a major risk factor for a poorer mental health prognosis [9–17].

Self-stigma, is also a barrier for patients to receive treatment early, so the recovery period is likely longer [18, 19].

Despite these important findings in developed countries, little is known about the role of internalized stigma of mental illness in Latin-America, a region that is characterized by different social, economic, and community conditions. Providing adequate care for the mentally ill and implementing needed public policies in particular contexts, requires evidence-based information on the level of self-stigma and its role in mental illness in different countries [20–22].

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Accordingly, the aim of this study was to investigate the degree of self-stigma in patients with schizophrenia from three countries in Latin-America (Bolivia, Peru, and Chile).

Method

Study participants

Data were collected through a survey of patients with a diagnosis of schizophrenia (ICD-10) [23] through the Public Mental Health Services program in three Latin-American cities: La Paz, Bolivia (32.8%); Arica, Chile (33.6%), and Tacna, Peru (33.6%).

Procedures

The study was approved by the Ethics Committee of the University of Tarapacá and the National Health Service of Chile. Two psychologists, who were part of the research team and supervised by the principal researcher, conducted the survey of the patients under the auspices of the mental health services of each country. The length of time of the evaluation was between 20 and 30 min.

Before the start of the survey, written informed consent was requested and received from the patient. The objectives of the study were explained as well as the voluntary nature of participation. No compensation was offered for participating in the study. At each center, during a 3-month window, all patients were invited to participate as they came for their monthly follow-up visits. The overwhelming majority of the patients agreed to participate.

Measures

Demographic and clinical data

The variables assessed were sex, age, ethnicity (Aymara and non-Aymara), educational level, employment status, marital status, family income (expressed in US dollars), age at onset of the disorder, duration of untreated psychosis (DUP), the number of hospitalizations in the last 3 years and severity of psychotic symptoms using the Positive and Negative Syndrome Scale for Schizophrenia (PANSS) [24]. For the purposes of this study, we only considered the PANSS total score.

All patients were administered antipsychotics. The presence or absence of add-on integrated treatment (psychotherapy, family psycho-education, and/or day care hospital in addition to pharmacological treatment) was also reported.

Internalized stigma of mental illness (ISMI) scale [9]

The ISMI is a self-rated 29-item questionnaire with five subscales (Alienation, Stereotype Endorsement, Discrimination Experience, Social Withdrawal, and Stigma Resistance). Each item is rated on a four-point Likert scale from 1 (strongly disagree) to 4 (strongly agree). The ISMI has been developed by Ritscher, Otilingam, and Grajales [9] in the United States to measure the subjective experiences of self-stigma, it has been validated since 2003, and the internal consistency and test–retest are acceptable for the original version. A high total score on the ISMI scale indicates more severe internalized stigmatization.

There are two interpretation of scores: the four-category method [25], where: 1.00–2.00: minimal to no internalized stigma; 2.01–2.50: mild internalized stigma; 2.51–3.00: moderate internalized stigma and 3.01–4.00: severe internalized stigma. The two-category method [26], where: 1.00–2.50: does not report high internalized stigma and 2.51–4.00 reports high internalized stigma. In this study, this last interpretation was used.

The original version of the ISMI scale was translated into Spanish by Bengochea-Seco et al. [27], this adapted version obtained good values of internal consistency and test–retest reliability, for the total score of the scale, as well as for the five subscales, except for the Stigma resistance subscale.

Statistical analysis

Socio-demographics, clinical characteristics, self-stigma variables are presented using measures of means and dispersion (standard deviation) for continuous data and frequency distribution for categorical variables. Comparisons were performed between the three countries (Bolivia, Chile, and Peru) using one-way analysis of variance (ANOVA) tests and Chi-square tests.

Results

Two hundred and fifty-three patients with schizophrenia participated in our study. The mean age of patients was 35.6 years (± 12.5 years) and 66.4% ($n = 164$) were male. Patients had a moderate severity of psychotic symptoms with a total PANSS score of 71.3 (± 28.2).

As shown in Table 1, differences in socio-demographic characterization between countries are small and not significant, with the exception of the sex, ethnicity and educational level. The sample in Peru had a lower proportion of male participants and persons of a low educational level than the samples in Chile and Bolivia. Chile had a smaller proportion of individuals of Aymara descent than the samples from the other two countries. Clinical outcome results

Table 1 Socio-demographic, clinical characteristics and Self-stigma by country

Socio-demographic	Chile N= 85 N (%)	Bolivia N= 83 N (%)	Peru N= 85 N (%)	P value
Sex (male)	58 (68.2%)	63 (75.9%)	43 (50.5%)	0.001
Age (years) ^a	37.9 (15.3)	33.7 (11.0)	35.2 (10.3)	0.084
Ethnicity (Aymara)	31 (36.5%)	48 (57.8%)	38 (44.7%)	0.020
Low educational level (≤ 12 years)	79 (92.9%)	73 (88.0%)	61 (71.8%)	< 0.001
Marital status (single)	77 (90.5%)	79 (95.1%)	77 (90.5%)	0.314
Unemployed	58 (68.2%)	54 (65.1%)	63 (74.1%)	0.434
Mean monthly family income (USD) ^a	666.0 (580.7)	229.7 (175.8)	313.3 (196.9)	< 0.001
Clinical characteristics				
Age at onset of the disorder (years) ^a	20.6 (7.5)	20.3 (5.4)	21.6 (6.5)	0.399
Duration of untreated psychosis (years) ^a	2.8 (4.7)	3.9 (5.9)	1.4 (3.4)	0.005
PANSS total score ^a	64.9 (26.6)	78.5 (25.4)	71.2 (31.2)	0.010
Mean number of hospitalizations in the last 3 years ^a	0.5 (1.2)	2.0 (1.5)	1.3 (1.5)	< 0.001
Pharmacological treatment only (percent) ^b	72 (84.7)	66 (79.5)	84 (98.8)	< 0.001
ISMI				
Alienation ^a	2.3 (0.79)	2.6 (1.01)	2.2 (0.63)	0.007
Stereotype endorsement ^a	1.9 (0.64)	2.0 (0.74)	2.1 (0.53)	0.123
Perceived discrimination ^a	2.4 (0.72)	2.5 (0.94)	2.2 (0.56)	0.070
Social withdrawal ^a	2.6 (0.81)	3.0 (0.91)	2.4 (0.61)	< 0.001
Stigma resistance ^a	2.4 (0.58)	2.4 (0.72)	2.3 (0.51)	0.405
ISMI total score ^a	2.3 (0.53)	2.4 (0.61)	2.2 (0.46)	0.057
Proportion above the midpoint 2.5	38.6%	48.7%	28.6%	

PANSS positive and negative syndrome scale for schizophrenia, ISMI internalized stigma of mental illness (ISMI) scale

Significant associations are in bold ($p < 0.05$)

^aSD Standard deviation

^bWithout add-on psychotherapeutic or social interventions

showed differences between countries, where Bolivia showed a higher level of severity of the disorder measured by the PANSS. In all countries, at least eight out of ten patients received pharmacological treatment only, with the proportion being highest in Peru.

The mean of ISMI for the total sample was 2.3 (SD = 0.54) and the level was not significantly different across the three countries. The mean values for each subscales were as follows: alienation: 2.3 (SD = 0.84); stereotype endorsement: 2.0 (SD = 0.65); perceived discrimination: 2.4 (SD = 0.76); social withdrawal: 2.7 (SD = 0.83) and stigma resistance: 2.4 (SD = 0.61). Also, the proportion above the midpoint of 2.5 on the total sample was 38.6%. The analyses also showed that 48.7% of patients from Bolivia report high internalized stigma compared to 38.6% from Chile and 28.6% from Peru but these differences were not significant. The only statistically significant differences on subscale scores by country were on two subscales: alienation ($p = 0.007$) and social withdrawal ($p = < 0.001$) with the highest scores for Bolivia. Peru reported the lowest levels of self-stigma on all of the

subscales except stereotype endorsement, although most of these differences were not significant.

Discussion

The findings of this study show that there are not significant differences in the overall levels of self-stigma between the three countries evaluated, however, Peru was the country with the best indicators and Bolivia's patients have the highest level of self-stigma on the two subscales where the differences were significant. These results are generally consistent with previous findings where it was also observed that patients with schizophrenia from Bolivia present with worse symptomatology, greater violent behavior, higher DUP, and greater number of hospitalizations [28] than patients from Chile and Peru. The high levels of self-stigma could be contributed to these reported differences.

On the other hand, considering the total sample, it is observed a higher level of internalized stigma in these Latin-American contexts compared to developed countries

such as US, Japan, and European countries, where it has been found a mean self-stigma scores ranged from 1.61 (SD=0.45) in Sweden to 2.36 (SD=0.40) in Lithuania, with a midpoint mean score of 2.22 (SD=0.57) in Macedonia [25, 29–33]. However, the levels of self-stigma in this study are similar to those observed in African countries, like Ethiopia and South Africa [34, 35]. This result is probably related to the socioeconomic conditions and public policies on mental health. The results that most stand out negatively in this sample have to do with Social withdrawal dimension of self-stigma, where these Latin-American countries have the highest score in comparison with any other country in the world [24, 28–32].

Previous studies conducted in Latin-America have revealed that patients with schizophrenia have poor social integration and functional activity. The social networks of these patients are small. They mainly consist of their caregivers and close relatives, with most patients having very limited contact with the community. In addition, severely mentally ill patients engage in few recreational activities and social interaction, and only a small percentage have an occupation outside the home. All this contributes to their poor perception of social support from persons outside of their family. The perception of lack of social support and the feeling of social withdrawal likely decrease the quality of life of these patients [36].

On the other hand, it is likely that the general perception of the Latin-American family as a highly cohesive family is changing. For example, Mora-Ríos and colleagues [36] report that families in Mexico have become the main source of discrimination (among patients with mental illness), with the consequence of greater social isolation experienced by the patient.

This study has some limitations that should be considered. First, the sample size; these participants are not representative of the entire Latin-American population of patients with schizophrenia; second, given its cross-sectional design, no conclusion can be drawn regarding causality. Third, the results should be considered with caution due to the lack of statistical power. Last, we did not perform multivariate analyses with adjustment for potential confounding factors as our goal was primarily descriptive in this brief report. Future analyses should explore the determinants of self-stigma using appropriate multivariate analyses. Nonetheless, the limitations of the study should be considered in the light of its strengths. This was the first study carried out in Latin-America that considers variation between patients' self-stigma across three countries. Future mental health research in Latin-America should devote greater attention to this topic and should seek to better understand the determinants and consequences of self-stigma at the micro (individual), mezzo (family), and

macro (society) level [17], giving special attention to the factors that are likely culturally relevant in Latin-America.

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