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Relationships between social stigma, stigma experience and self-stigma and impaired quality of life in schizophrenia accross **three Latin-America countries.**

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Abstract (limited 250)

Background. The relationships between stigma and quality of life in schizophrenia (QoL) have been extensively explored but have mostly focused on self-stigma and self-esteem and have never been explored in Latin-America.

Objective. To determine which stigma dimensions were associated with QoL in a sample of community dwelling SZ subjects of three Latin-America countries.

Methods. Stabilized outpatients with SZ were recruited in 3 Mental Health Services in three Latin American countries: Bolivia (N = 83), Chile (N = 85) and Peru (N = 85). Stigma and QoL-SZ were evaluated by self-administered questionnaires, the Internalized Stigma of Mental Illness scale (ISMI-12) and the SQoL-18.

Results. 253 participants were included. In multivariate analyses, QoL has been associated with each stigma dimension (social stigma, stigma experience and self-stigma), independently of age, gender, education level, ethnicity, age at illness onset, illness symptomatology and mental health treatment. More specifically, social stigma was significantly associated with impaired psychological and physical well-being, self-esteem and friendship. Self-stigma was significantly associated with impaired psychological well-being, self-esteem and autonomy.

Conclusion. The present results confirm the importance of stigma in QoL of SZ subjects and identify new targets to develop stigma-orientated programs. Most of the previous programs have focused on self-stigma while social stigma has shown to be associated with a wide range of impaired QoL areas. Stigma and QoL may have a bidirectional relationship and targeting some specific QoL areas (like autonomy through self-empowerment approaches) may also improve the effectiveness of these programs to reduce stigma impact on the quality of life of subjects with schizophrenia. Future studies should also explore differences across countries as subjects from Bolivia were more frequently Aymara and reported higher stigma and lower QoL than SZ subjects from other countries.

Keywords: Stigma, schizophrenia, quality of life, well-being.

Introduction

Schizophrenia is the mental disorder that is the most associated with stigma in general populations around the world [1]. People with a schizophrenia-spectrum diagnosis experience higher levels of stigma compared to any other mental health diagnosis [2, 3]. The findings of a systematic review by Gerlinger and colleagues (2013) indicate that from one-third to one-half of patients with schizophrenia (SZ) feels shame as a consequence of the disorder [4]. Stigma is also a barrier for early antipsychotic treatment onset, and increased duration of untreated psychosis has been associated with worse prognosis [5].

Beyond illness course, stigma has also been extensively associated with impaired quality of life (QoL) in SZ in multiple countries covering mostly Asia, some European and African countries and the USA [1, 6–14, 14–37]. No study has been carried out in Latin-America countries to date, while society plays a major role in stigma experience [38].

Moreover, the previous studies have mostly explored the specific association of self-stigma with impaired self-esteem in a purpose of developing self-stigma targeted interventions. These interventions have shown promising preliminary results [3]. Exploring the multiple dimensions of stigma may improve the effectiveness of these interventions. Most of the existing stigma instruments explored three stigma dimensions: perceived/social stigma (defined by the social dimension of stigma, i.e. being side-lined by mentally healthy people), experienced stigma (defined by the subjective feeling of experiencing discrimination) and self-stigma (defined by “*internalization of public stigma*” or as “*the product of internalization of shame, blame, hopelessness, guilt and fear of discrimination associated with mental illness*”) [39–41]. We confirmed these three dimensions in a recent study validating the ISMI-12 scale [42].

The aim of this study was to determine which stigma dimensions were associated with QoL in a sample of stabilized community dwelling SZ subjects of three Latin-America countries.

Methods

Study participants

SZ outpatients were consecutively recruited between May 2012 and February 2013 in the three public ambulatory psychiatric care centers of three areas: Arica, northern Chile (N=85, 33.6%), Tacna, southern of Peru (N=85, 33.6%), and La Paz, Central-Western of Bolivia (N=83, 32.8%). The three centers shared similar characteristics in terms of size, type of treatment delivered to patients, professionals and free access of care.

Inclusion criteria

All stabilized community-dwelling patients diagnosed with schizophrenia according to the criteria of International Classification of Diseases (ICD), 10th version were included in this study. Schizophrenia diagnosis was confirmed within a standardized interview. Stabilization was defined by the absence of current acute psychotic episode at the time of evaluation and absence of ongoing change in pharmacological treatment in the last 2 months.

Exclusion criteria

Patients with a history of neurological disorders (including stroke, epilepsy and head injury) or all illnesses affecting central nervous system were not included in the present study.

Procedures

Two psychologists, who were part of the research team, trained for scale evaluation, and supervised by the principal researcher (ACU), conducted the evaluations of the participants under the auspices of the mental health services of each country. The length of time of the evaluation was between 20-30 minutes.

Stigma assessment

The Internalized Stigma of Mental Illness scale (ISMI-12) [42] is the short form of one of the most widely used measurements of internalized stigma in mental health research, the ISMI-29 (Ritsher, Otilingam & Grajales, 2003; Ritsher & Phelan, 2004; Lysaker, Roe & Yanos, 2007; Boyd, Adler, Otilingam & Peters, 2014). The dimensions were named according to their constitutive items: social stigma (4 items), stigma experience (4 items), and self-stigma (3 items). The 12 items are detailed in the Appendix. The three dimensions were independent based on principal component factor analyses with varimax rotation. A higher score was associated with higher self-reported stigma in each dimension.

Quality of life

QoL was assessed using the shortened questionnaire to assess quality of life in schizophrenia (S-QoL18), a self-administered QoL questionnaire designed for people with schizophrenia [43] and validated in Latin America [44]. The S-QoL-index ranges from 0, indicating the lowest QoL, to 100, the highest QoL. Eight dimensions are explored in this scale: PsW: psychological well-being; SE: Self-Esteem; RFa: family relationships; RFr: relationships with friends; RE: resilience; PhW: physical well-being; AU: autonomy; SL: sentimental life. The items of each dimension are described in the Appendix.

Demographic and illness characteristics variables

Age, gender, ethnicity (Aymara and non-Aymara), marital status (with or without partner), educational level (≥ 12 years or < 12), illness duration, family income (measure of the total salary per month for all members of the family, expressed in US dollars), and age at illness onset were reported. Concerning ethnicity, the Aymara is the largest ethnic group in the region, with a population of 2 million people, and has lived in the Andes Mountains for centuries. Recent generations of Aymara have undertaken a massive migration from rural

towns to large cities and, thus, receive healthcare services from the same clinics as non-Aymara individuals [45].

Current symptomatology was evaluated with the Positive and Negative Syndrome scale for Schizophrenia (PANSS)[46]. This 30-item, 7-point (1–7) rating scale has been specifically developed to assess **current symptomatology** in SZ individuals. **The 3-factors structure (positive factor, negative factor and general psychopathology) was used.** The PANSS has been translated and validated in Spanish [47]. All patients were administered antipsychotics. The presence or absence of add-on integrated treatment (defined by psychotherapy, family psychoeducation, and/or day care hospital in addition to pharmacological treatment) were also reported.

Ethical considerations

Before the start of the study, written informed consent was requested and received from the patient and her/his primary caregiver. The objectives of the study were explained as well as the voluntary nature of participation. No compensation was offered for participating in the study. The study was approved by the Ethics Committee of the University of Tarapacá and the National Health Service of Chile.

Statistical analysis

Associations between QoL scores and the continuous variables (**social stigma, stigma experience, self-stigma,** age, family income, age at illness onset, **illness duration,** symptom severity) were analyzed using **Pearson's** correlation tests. Means-based comparisons of the S-Qo18 **index** between various subgroups (men vs. women, high vs. low education level, Aymara vs. Non-Aymara, pharmacological vs. pharmacological + non pharmacological/integrated treatment) were calculated using **Student t** tests.

Multivariate analyses using multiple linear regression (simultaneous model) were then performed to determine variables potentially associated with QoL levels. The S-QoL 18 index and each of its dimensions were considered as separate dependent variables. The variables relevant to the models were selected from the univariate S-QoL18 index analysis based on a threshold $p\text{-value} \leq 0.20$. Gender was included in the models because of its sociodemographic interest.

The final models incorporated the standardized β coefficients, which represent a change in the standard deviation of the dependent variable (QoL) resulting from a change of one standard deviation in the various independent variables. The independent variables with the higher standardized beta coefficients are those with a greater relative effect on QoL.

This study was a confirmatory analysis. No correction for multiple testing has therefore been carried out, which is consistent with recommendations [48]. All the tests were two-sided. Statistical significance was defined as $p < 0.05$. The statistical analyses were performed using the SPSS version 20.0 software package (SPSS Inc., Chicago, IL, USA).

Results

Overall, 253 community-dwelling SZ patients were recruited in the present study, with a mean age of 35.6 years, 164 (66.4%) men and a mean illness duration of 14.6 years. The characteristics of the sample are presented in Table 1. Differences across countries are presented in Supplementary table 1. The rate of Aymara subjects was higher in Bolivia compared to Chile and Peru (57.8% vs. 36.5% and 44.7% respectively).

In univariate analyses, decreased S-QoL index was associated with all stigma level dimensions (social stigma $R = -0.38$, $p < 0.001$, stigma experience, $R = -0.47$, $p < 0.001$, self-stigma $R = -0.42$, $p < 0.001$), current illness severity (PANSS total score $R = -0.37$, $p < 0.001$), ethnicity (Aymara vs. non-Aymara 52.27 vs. 55.97, $p = 0.042$), education level (≥ 12 years VS. < 12 years: 52.70 vs. 62.47, $p < 0.001$). In multivariate analyses, QoL has been associated with

each stigma dimension (social stigma, stigma experience and self-stigma), independently of age, age at illness onset, illness symptomatology (PANSS score), gender, education level, ethnicity, and mental health treatment (Table 2).

More specifically, social stigma was significantly associated with impaired psychological and physical well-being, self-esteem and relationships with friends. Self-stigma was significantly associated with impaired psychological well-being, self-esteem and autonomy. Stigma experience was only associated with impaired sentimental life. None of the stigma dimension was associated with impaired resilience.

Discussion

Altogether, the results of the present study may be summarized as follows: in a sample of stabilized community dwelling SZ subjects of 3 Latin-America countries, stigma was associated with impaired QoL. The associations between impaired QoL and stigma varied according to each stigma dimension. Impaired psychological well-being and self-esteem were both associated with social- and self-stigma. Social stigma was specifically associated with impaired physical well-being and friendship, while self-stigma was associated with impaired autonomy and stigma experience with impaired sentimental life.

Our results have confirmed that stigma is associated with impaired QoL in stabilized SZ subjects in Latin-America countries. This association has been consistently reported across the world and for the first time in Latin-America countries, suggesting that schizophrenia appears as a specific mental illness that provides high stigma levels whatever the society, cultural beliefs or global education level. This phenomenon was recently highlighted in a French/German study exploring the impact of the term “schizophrenia” as well as the symptoms of the illness as sources of stigma in the general population [49]. Given that our

study is the first to use the ISMI-12 scale to evaluate stigma, no direct comparison with other studies carried out in other countries could be done, which is a limit of the present results.

The association between self-stigma and impaired self-esteem has been confirmed in the present study, consistently with previous studies [9, 17, 31, 32, 50, 51]. Beyond this association, we have also found that self-stigma was also associated with impaired psychological well-being and impaired autonomy. No study has specifically explored the association between stigma and autonomy in schizophrenia to date. On the contrary, recovery has been extensively shown to be associated with improved stigma in SZ subjects [52–54]. The association between self-stigma and impaired autonomy may be mediated by cognitive deficits [18, 25, 26] or social anxiety [17] that were previously found to be associated with self-stigma but that have not been explored here, which is a limitation of the present work. Self-stigma and impaired autonomy may have a bidirectional relationship, targeting both self-stigma (by specific cognitive behavioral interventions) as well as autonomy (by recovery/psychosocial interventions) may therefore improve the psychological well-being of SZ subjects.

Our results suggest that social stigma was also associated with impaired self-esteem and psychological well-being in subjects with schizophrenia. Social stigma is the feeling of being sidelined from the mentally healthy people while internalized stigma is the feeling of deserving it. The stigma-orientated interventions may therefore target not only the feeling of deserving isolation but directly some beliefs underpinning social stigma. For example, patients experiencing social stigma report that having mental illness makes them need other to make decision for them, that mentally healthy people cannot understand them or that they need to stay away from social situations to protect their relatives from embarrassment. These beliefs may be directly targeted by cognitive behavioral interventions. Acceptance and commitment therapy may be particularly suitable psychotherapy for these patients [55]. This

third wave cognitive behavioral therapy includes mindfulness, acceptance and compassion that may specifically improve stigma in SZ subjects [56].

Altogether, our results suggest that social stigma and self-stigma are associated with a wider range of impaired QoL areas than stigma experience. Those reporting high level of stigma experience in our study reported also impaired levels of sentimental QoL. Sentimental life has been poorly explored in schizophrenia to date [57], this area of QoL should be specifically explored in future studies.

Limits. The present data is cross-sectional and longitudinal studies may yield relevant insight on the mechanisms of the association between stigma and QoL in SZ subjects. Self-perceived cognitive deficits have been associated with both QoL of SZ subjects and stigma and have not been explored in the present study. Stigma resistance, i.e. the capacity to resist to stigma [27] and the specific issue of job seeking [33] have also not been explored. Subjects from Bolivia were more frequently Aymara, which may explain the lower QoL score and higher stigma levels reported in this country. Future studies with larger samples should be carried out to examine country differences and their impact on stigma in SZ subjects.

Strengths. The use of standardized questionnaires and the inclusion of important confounding factors may be mentioned in the strengths of the present study. The impact of stigma on SZ QoL has been explored for the first time in Peru, Bolivia and Chile. Psychotherapy has been taken into account in our analyses, which had not been done in most of the previous studies.

Perspectives. Different interventions have been explored to reduce stigma in schizophrenia. Some countries have renamed schizophrenia to diminish its associated stigma, however with little evidence for effectiveness [58]. The impact of social media on stigma remains also insufficiently explored [38, 59]. A recent review has shown small to medium

effects of contact interventions, educational interventions, mixed contact and education, family psychoeducation programs, and hallucination simulations and has concluded that it was needed to understand the active ingredients of these interventions to improve their effectiveness [60]. Another review has shown the lack of data on the impact of biogenetic causal beliefs on stigma [61]. In summary, further studies are needed to improve stigma coping in SZ subjects and as a consequence their QoL. As patient sociodemographic and illness factors may influence healthcare satisfaction and experience of care [62], future studies should also explore if stigma may impact patients' healthcare satisfaction and experience of care [63].

Conclusion

Social stigma and self-stigma are associated with a wide range of QoL areas including impaired self-esteem and psychological well-being. Impaired autonomy has also been specifically associated with self-stigma. Each stigma dimension relies on beliefs that should be specifically targeted in stigma-orientated cognitive and behavioral interventions to improve the QoL of SZ subjects.

Conflicts of interest: no conflict to disclose.

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