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## Highlights

- This study examined the relationship between self-stigma and depression in people with schizophrenia.
- Self-stigma was strongly associated with depression over time.
- Feeling discriminated against and having difficulties considering the positive aspects of the illness could predict and partially contribute to worsened depressive symptoms.

ACCEPTED MANUSCRIPT

**Title:** The relationship between self-stigma and depression among people with schizophrenia-spectrum disorders: a longitudinal study.

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## ABSTRACT

Harmful consequences of self-stigma in schizophrenia are well established in the literature, but its relationship with symptomatology remains unclear. Self-stigma describes the process by which some patients eventually accept, adhere to and apply to themselves the stereotypes associated with schizophrenia. This study aims to describe self-stigma experienced by people with schizophrenia in French-speaking Switzerland and to examine the relationship between self-stigma and depression. This was a longitudinal study including 80 participants. Correlation and regression analyses were used to examine the relationship between self-stigma and depression over three points of time. Correlations between Stigma Scale subdimensions and sociodemographic variables indicated that age and duration of illness were associated with the *discrimination* subscale. Self-stigma was strongly correlated with depression over time, whereby higher scores of self-stigma were associated with higher depression. More precisely, the more the patient felt *discriminated* against and the less he or she perceived the *positive aspects* of his or her illness, the greater the symptoms of depression. This study highlights the severity of self-stigma endorsed by people with schizophrenia in French-speaking Switzerland. The results provide new knowledge about self-stigma and its potential impact on depressive symptoms. Implementation of self-stigma assessment in clinical practice will allow distinctions to be made between the impact of self-stigma and the consequences of schizophrenia to recommend appropriate intervention.

Keywords: Internalized stigma; Recovery; Stigma; Stereotypes; Mental illness; Psychotic Disorders; Discrimination; Switzerland

## 1. Introduction

Self-stigma affects nearly one-quarter of people with schizophrenia in Europe, for which this issue constitutes a major obstacle to life projects, psychological recovery and access to care (Brohan et al., 2010b; Fung et al., 2008; Omori et al., 2014). Self-stigma deserves increased interest as self-stigma limits the use and participation in care of people with schizophrenia and severely affects their quality of life (Omori et al., 2014). Schizophrenia is perceived particularly negatively by society. Patients are rejected and described as dangerous or unpredictable (Dinos et al., 2004; Lundberg et al., 2008; Wood et al., 2014). People with schizophrenia suffer more acutely and frequently from self-stigma than other psychiatric diagnoses, such as bipolar disorders (Chang et al., 2016; Ritsher and Phelan, 2004a; Sarisoy et al., 2013). The results from a cross-sectional study conducted in 14 European countries indicated that 41.7% of users of mental health organizations, mostly with schizophrenia, reported moderate to high levels of self-stigma (Brohan et al., 2010a). Corrigan et al. defined self-stigma as an evolutionary process in four phases; (1) awareness of the associated stereotype, (2) agreement to this stereotype, (3) applying the stereotype to one's self, (4) decrease in self-esteem (Corrigan et al., 2011). This model shows that the stage of self-stigmatization is actually a late consequence of the process. Corrigan et al. refer to the negative impact of self-stigma on life projects in terms of the "Why Try Effect". According to the authors, the "Why Try Effect" brings together three components: self-stigma, mediators such as self-esteem and self-efficacy, and lack of achievement of life goals (Corrigan et al., 2009). It is therefore a major issue for health care professionals who offer support focused on psychological recovery.

Depressive symptoms in schizophrenia are often difficult to distinguish from negative symptoms, extrapyramidal side effects or episodes of dysphoria (Bartels and Drake, 1988). Many studies have found that people who internalize the stereotypes associated with their illness were more depressed (Ritsher et al., 2003) (Aukst-Margetic et al., 2014; Belvederi Murri et al., 2016; Bouvet and Bouchoux, 2015; Gerlinger et al., 2013; Kao et al., 2016; Park, 2015; Park et al., 2013; Ritsher and Phelan, 2004a; Rossi et al., 2017; Schrank et al., 2014; Sibitz et al., 2011; Vauth et al., 2007; Yanos et al., 2008). Although, according to a systematic review of the literature, the results concerning this

association remain conflicting, it is quite clear that self-stigma can predict nearly a third of the variance of depression (Aukst-Margetic et al., 2014). Longitudinal research has also shown that self-stigma was significantly associated with an increase in depressive symptoms over time (Boyd et al., 2016a; Ritscher and Phelan, 2004a).

Despite a growing amount of research on self-stigma over the last ten years, factors involved in the process of self-stigma and relationship with symptomatology are still unclear, and the results lack generalizability (Livingston and Boyd, 2010; Omori et al., 2014). The way in which internalized stigma affects recovery is a crucial issue to develop targeted intervention (Yanos et al., 2008). The aim of this study was to describe the self-stigma experienced by patients with schizophrenia and examine the association of this variable with depression over time. The hypothesis was that the greater the self-stigma is, the more severe the depression.

## 2. Method

### 2.1 Study design and participants

Data for this study were drawn from a randomized, controlled clinical trial testing the effectiveness of the Positive Emotion Program for Schizophrenia (PEPS) on apathy and anhedonia (Favrod et al., 2019). Participants in this study correspond to the participants in the intervention and control groups of the primary study.

### 2.2 Measures

Data were collected during an interview with blind trained evaluators at inclusion of the participants into the study (T0), at the end of the intervention two months later (T1), and six months later (T2).

- The Stigma Scale is a self-questionnaire that includes three subdimensions: *discrimination*, *disclosure* (reluctance to openly mention psychiatric illness for fear of being discriminated against) and difficulty in considering the *positive aspects* of the disease. Scores range from 0 to 36, and the higher the scores are, the higher the stigma perceived by the participants (King et al., 2007). The short version of the Stigma Scale has been validated in French, with three items per dimension (Morandi et al., 2013).

- The Calgary Depression Scale for Schizophrenia (CDSS) includes nine items: observed depression, hopelessness, self-deprecation, guilt-themed reference ideas, pathological guilt, morning depression, early awakening, suicidal thoughts, and observed depression (Addington et al., 1990). A score equal to or greater than 6 indicates the presence of a clinically major depressive episode (Rybakowski et al.).

### 2.3 Statistical analysis

A descriptive analysis of sociodemographic and clinical variables was performed to obtain means and standard deviations for continuous variables and distributions for categorical variables. Assessment of group differences was undertaken through comparison tests (Student's t-test and chi-square test). A bivariate analysis of the variables was performed using the Pearson correlation coefficient between continuous quantitative variables and Student's t-tests between continuous and dichotomous variables. Multivariate linear regressions were performed to determine the reciprocal influences of self-stigma and depression for the initial measurement and their evolution over time. The CDSS total score and subdimensions were introduced as independent variables, and the total score and subdimensions of the Stigma Scale were introduced as dependent variables with the stepwise method to determine if self-stigma could predict depressive symptoms. To examine the potential impact of the initial level of self-stigma on the evolution of depression scores, linear regressions were also estimated, controlling for participation in PEPS and for the T0 depression score. Evolution of depression score was calculated as T1-T0 and T2-T0. Given the lack of missing data, these were not replaced (2 self-stigma questionnaires were not completed, 6 participants dropped out at the posttest and 1 at the six-month follow-up) and only the present values were analyzed. Statistical analyses were conducted using IBM SPSS version 22. The significance level for all tests was set at  $\alpha=.05$ .

## 3. Results

### 3.1 Sociodemographic and clinical characteristics

The participants' characteristics are reported in Table 1. They were mostly male (61.3%) and the average age was 39.9 years ( $SD = 10.9$ ), with a disease duration of 16.1 years ( $SD = 9.7$ ). Approximately four out of five participants in the total sample were single, with no children, and just

over half lived alone (55%). The highest level of training achieved by more than one-third was compulsory schooling, and 61.3% worked in sheltered workshops while receiving a disability pension (97.5%).

### 3.2 Self-stigma scores

At baseline, the mean Stigma Scale score for the entire sample was 20.82 (SD = 4.93) out of a theoretical maximum of 36. The mean score for the subdimension *disclosure* was 7.88 (SD = 3.22), *discrimination* dimension score was 6.90 (SD = 2.74) and the score for the difficulty in considering the *positive aspects* of the disease was 6.04 (SD = 2.81).

### 3.3 Correlates of self-stigma

People who lived in a sheltered house, compared to those who lived in an apartment (19.47 (SD = 4.58) vs 22.24 (SD = 4.93)), reported lower levels of self-stigmatization at T0 ( $t(76) = -2.56, p = .01$ ). No associations were found between total score on the Stigma Scale and age ( $r = .81, p = .48$ ) or duration of illness ( $r = -.02, p = .86$ ). The total score on the self-stigma test was also not associated with sex ( $t(76) = 0.122, p = .34$ ), education level ( $r = -.18, p = .11$ ), being single ( $r = -.22, p = .05$ ), or working in sheltered employment ( $r = .34, p = .77$ ).

Regarding self-stigma subscales, age ( $r = .23, p = .04$ ) and duration of illness ( $r = .24, p = .03$ ) were correlated with the scores on the discrimination subscale. People who lived in a independent accommodation appeared more reluctant to disclose their disease at T1 than those who lived in a sheltered house (8.14 (SD = 2.57) vs. 6.54 (SD = 2.57)) ( $t(70) = -2.65, p = .01$ ).

At T1, men had a significantly higher score than women in the difficulty of considering the positive aspects of the disease (6.44 (SD = 2.41) vs 5.13 (SD = 1.89) for men and women, respectively). This score was reversed, suggesting that women were more aware of potentially positive aspects of the disease ( $t(70) = -2.50, p = .01$ ). However, this difference was not significant at T0 and T2. On the other hand, women had a significantly higher average discrimination score at T2 than men (7.03 (SD = 2.55) vs 6.49 (SD = 2.51)), suggesting that they felt more discriminated against because of their mental disorder ( $t(70) = 2.33, p = .02$ ).



### 3.3 Correlations of self-stigma with depression

Self-stigma and depression were correlated ( $r = .41, p = .001$ ) over time (T1:  $r = .44, p = .001$ ; T2:  $r = .41, p = .001$ ). There was also a positive correlation between the discrimination subscale and depression at T1 and T2 ( $r = .39, p = .001$ , respectively  $r = .33, p = .005$ ). The disclosure dimension was also correlated with depression at T0 and T2 ( $r = .24, p = .03, r = .27, p = .02$ ). Only the difficulty of considering the positive aspects was not correlated with depression.

The research hypothesis was that the higher the self-stigmatization of the patient, the greater his or her depressive symptoms. To test this hypothesis, multivariate regression models were used, introducing depression as a dependent variable and the total self-stigma and the subdimensions as independent variables. The results of regression analyses showed that self-stigma predicted higher depressive symptoms ( $R^2 = .17, F(1,76) = 15.09, p = .001$ ). The higher the self-stigma, the higher the depression score increased ( $\beta = 0.41, p = .001, IC\ 95\% [0.19 ; 0.58]$ ) (Figure 1). Subscale analyses show that higher depression was mainly predicted by the dimension discrimination and difficulty of considering the positive aspects ( $R^2 = .13, F(2,75) = 6.59, p = .002$ ). In other words, the more the patient felt discriminated against and the less he or she perceived the positive aspects of the illness, the more severe his or her symptoms of depression were ( $\beta = 0.33, p = .003, IC\ 95\% [0.20 ; 0.94]$  et  $\beta = 0.25, p = .025, IC\ 95\% [0.06 ; 0.88]$ ).

Total self-stigma did not predict the evolution of depression between T0, T1 and T2, controlling for depression at T0 and participation in PEPS (T1-T0:  $R^2 = 0.55, F(3,68) = 28.13, p = .44$ ; T2-T0:  $R^2 = 0.50, F(2,68) = 33.51, p = .19$ ). By introducing self-stigmatization sub-dimension scores only the coefficients of depression at T0 and participation in PEPS were significant ( $\beta = -0.196, p = .025, \beta = -0.73, p = .001$ ). The depression score at T0 was therefore the main predictor of the evolution of depression at T1, as well as at T2 with participation in PEPS.

## 4. Discussion

This study highlighted the problem of self-stigmatization and its consequences for patients with schizophrenia in French-speaking Switzerland. Self-stigma significantly affected patients who are

especially afraid to disclose their disease. The results suggested that the more patients self-stigmatized, the more depressed they felt.

In this study, the total score on the Stigma Scale was not associated with any sociodemographic variables, similar to findings shown earlier in several studies and a systematic review (Holubova et al., 2016a; Holubova et al., 2016b; Lysaker et al., 2007; Singh et al., 2016). However, regarding subdimensions of self-stigma, the results indicated that as age and duration of the illness increased, the feeling of being discriminated against was important. These results were partially confirmed by a cross-sectional study, which showed that the sooner the disease was diagnosed, the greater the perceived discrimination was important (Holubova et al., 2016b). The years of life that a person went through with the disease naturally exposed them to more negative reactions, discriminatory situations or stigmatizing remarks. Another possibility could be that there are differences in experiences of stigma according to the generation of the patients related to the evolution of psychiatric care. The older people may have experienced a more discriminating form of psychiatry (institutionalization, high doses of neuroleptics, restriction of individual liberties) than younger people who have gone through the community shift, with minimal doses of neuroleptics and laws protecting individual liberties (Bonsack and Favrod, 2013).

Longitudinal studies would be useful in clarifying the evolving characteristics of the self-stigmatization process and the strategies developed to resist stereotypes. In this sample, women perceived the potentially positive aspects of the disease more than men did but also felt more discriminated against because of their mental disorder. This sex influence was raised by the Gamian European study as well as other research showing that the feminine sex is more strongly associated with stereotypes (Brohan et al., 2010b; Singh et al., 2016). Maintaining social skills, a better therapeutic alliance, a proactive attitude in treatment, and a supportive environment are sex-differentiating factors in schizophrenia that could promote a more positive view of the disease in women (Falkenburg and Tracy, 2014). Nevertheless, they are also more discriminated against in society and socially and economically disadvantaged solely because of their sex. Role expectations put additional pressure on women who suffer from schizophrenia and can create a sense of discrimination when they fail to respond. On the other hand, men often endure more criticisms and less understanding

from families and friends, which probably limits their perception of the potentially positive aspects of their illness (Falkenburg and Tracy, 2014).

Confirmation of a relationship between self-stigma and depression at a later stage was a major result, coinciding with several studies (Bouvet and Bouchoux, 2015; Gerlinger et al., 2013; Livingston and Boyd, 2010; Lysaker et al., 2007; Park et al., 2013; Ritsher et al., 2003; Vauth et al., 2007). The results showed that a higher level of self-stigma predicted higher depressive symptoms. Depressive symptoms were higher mainly when the feeling of being discriminated against and the difficulty of considering the potentially positive aspects of the illness were high. According to Link's modified labeling theory (1989), depression was one of the negative consequences secondary to anticipated discrimination. (Link et al., 1989). The hypothesis of this study was thus confirmed and highlighted that self-stigma was likely a contributing factor to high symptoms of depression. Ritsher (2004) and Boyd (2016) showed that the initial level of self-stigma was a determining factor for the evolution of depressive symptoms, which was not observed in this study (Boyd et al., 2016b; Ritsher and Phelan, 2004b). However, Ritsher's (2004) analysis focused on a small sample ( $n = 47$ ) and a single measurement at four months, which is a very short time span relative to the years of life living with the disease, and Boyd's results are difficult to generalize since they examined a sample of homeless people and veterans of the army.

#### 4.1 Strengths and limitations

The main strength of this study was to bring unprecedented results concerning the self-stigmatization experienced by people with schizophrenia in French-speaking Switzerland. The relatively large sample size was satisfactory given the complexity of recruiting participants in psychiatric settings.

The results of this study suggest that the experience of stigmatization might differ between men and women, therefore specific research should be conducted to better understand the influence of sex on the self-stigma process and resources mobilized to deal with it. The sample size and the environment in which the participants were recruited also do not allow direct generalization of the results beyond

larger populations of people with schizophrenia. Since self-stigma is a major barrier to accessing health services, it would also be necessary to recruit participants outside health care settings.

Using the Stigma Scale was another limit of this study; according to the author of the French validation, this scale would rather assess perceived stigma than self-stigma (Morandi et al., 2013). This assumption refers to Patrick Corrigan (2002), according to whom the awareness of stereotypes does not systematically generate a process of self-stigma (Corrigan and Watson, 2002). Conversely, King (2007) indicated that the psychometric validation of the Stigma Scale showed a similar content to that of the Internalized Stigma of Mental Illness (ISMI), developed specifically to measure self-stigma (King et al., 2007; Ritsher et al., 2003). The selection criteria of presenting a score of at least 2 on the global anhedonia scale of the SANS, even if low, may have selected a sample more depressed than a sample without this criterion.

#### 4.2 Recommendations

To act more effectively and directly with the people concerned, self-stigma appears today as an axis of intervention complementary to campaigns against stigmatization in the general population. Integrating the evaluation of self-stigma into patient follow-up would allow nurses to initiate a discussion on this topic and to propose targeted interventions and thus reduce the negative impact of stereotypes on patients. Nurses also play a central role in communicating about the recovery of psychiatric illness to the public to effectively combat the stereotypes (Corrigan et al., 2016). Over the past decade, programs have offered a variety of approaches to learning to cope with stigma and self-stigma. Most psychosocial interventions that address the self-stigma of people with a diagnosis of schizophrenia take place in groups and mobilize approaches such as psychoeducation to refute false beliefs about schizophrenia or cognitive approaches to acquire and train skills to identify and combat self-stigma (Fung et al., 2011; Wood et al., 2016). Yanos & al. developed for instance the "Narrative Enhancement and Cognitive Therapy (NECT)", that use narrative reinforcement and cognitive therapy (Yanos et al., 2011). Narrative helps participants to openly share their experiences, give them meaning and benefit from interactions with peers and facilitators, without being inhibited by the weight of self-stigma (Yanos et al., 2011).

More longitudinal studies are needed to establish causal links between self-stigma and depression. The collaboration of people with schizophrenia is essential to develop interventions that are relevant and appropriate for user needs. Finally, the translation or development of evaluation tools in French would encourage the use of these instruments in clinical practice.

**Declaration of interest**

The authors declare that they have no competing interests.

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**Table 1:** Sociodemographic characteristics of the participants

|  | Total sample<br>(n = 80) |
|--|--------------------------|
| Male, n (%)                              | 49 (61.3)                |
| Female, n (%)                            | 31 (38.8)                |
| Age, M (SD)                              | 39.90 (10.9)             |
| Min – Max                                | 19 – 64                  |
| <b>Education</b>                         |                          |
| Compulsory education noncompleted, n (%) | 8 (10.0)                 |
| Compulsory education , n (%)             | 33 (41.3)                |
| Apprenticeship, n (%)                    | 25 (31.3)                |
| Higher education, n (%)                  | 14 (17.5)                |
| <b>Personal status</b>                   |                          |
| Single, n (%)                            | 67 (83.8)                |
| No children, n (%)                       | 64 (80.0)                |
| Living alone, n (%)                      | 44 (55.0)                |
| Living in sheltered accommodation, n (%) | 40 (50.0)                |
| <b>Employment</b>                        |                          |
| Sheltered employment , n (%)             | 49 (61.3)                |
| Unemployed, n (%)                        | 15 (18.8)                |
| Disability pension, n (%)                | 78 (97.5)                |

**Table 2:** Clinical characteristics of the participants (N=80)

| <b>Diagnosis</b>                |              |           |
|---------------------------------|--------------|-----------|
| Schizophrenia, n (%)            | 66 (82.5)    |           |
| Schizoaffective disorder, n (%) | 14 (17.5)    |           |
|                                 | M (SD)       | Min - Max |
| Duration of illness in years    | 16.07 (9.67) | 0 - 45    |
| <b>Stigma scale</b>             |              |           |
| Discrimination                  | 20.82 (4.93) | 9 - 32    |
| Disclosure                      | 6.90 (2.65)  | 3 - 12    |
| Positive aspects                | 7.88 (2.88)  | 3 - 12    |
| Positive aspects                | 6.04 (2.41)  | 3 - 12    |
| <b>CDSS</b>                     | 5.61 (4.65)  | 0 - 20    |

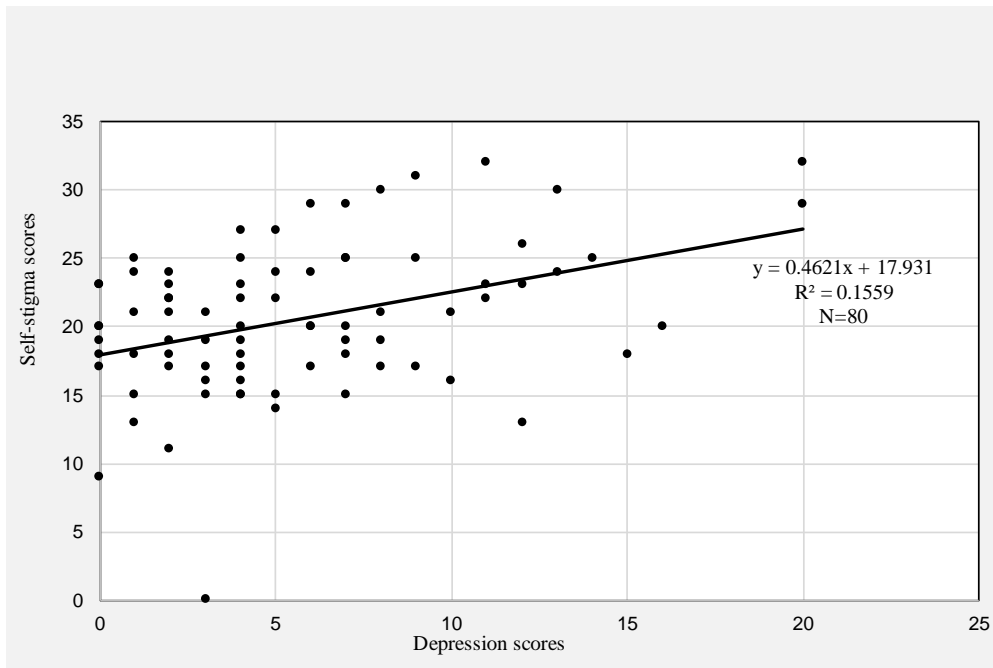


Figure 1. Scatter plot of the relationship between self-stigma and depression