

Title

Is living with psychosis demoralizing? Insight, self-stigma and clinical outcome among people with schizophrenia across one year

Running title

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ABSTRACT

Background: Lack of insight is a major target in the treatment of schizophrenia. However, insight may have undesirable effects on self-concept and motivation that can hinder recovery. This study aimed to examine the link between insight, self-stigma and demoralization as predictors of symptoms and functioning.

Methods: Insight, self-stigma, depressive and psychotic symptoms, and functioning were assessed among 133 outpatients with schizophrenia at baseline and twelve months later. The data were analyzed by hierarchical multiple linear regressions.

Results: More insight at baseline and an increase in self-stigma over twelve months predicted more demoralization at follow-up. Insight at baseline was not associated with any outcome variable, but self-stigma at baseline was related to poorer functioning and more positive symptoms at follow-up. More demoralization at baseline predicted poorer functioning twelve months later. Demoralization did not mediate the relationship between self-stigma at baseline and functioning after one year.

Discussion: Given the decisive role of self-stigma regarding recovery from schizophrenia, dysfunctional beliefs related to illness and the self should be addressed in treatment. Different psychotherapeutical approaches are discussed.

Keywords: Insight, self-stigma, demoralization, recovery

1. Introduction

Insight – defined as the awareness of having a mental disorder, its symptoms, consequences, and need for treatment – is one of the main targets in research about and treatment of schizophrenia. Lack of insight is a common phenomenon in schizophrenia with reported rates between 30% and 80% (Mintz et al, 2003; Lincoln et al., 2007). It is an established risk factor for mal adherence to treatment and poor clinical outcome, such as high levels of positive and negative symptoms, frequent relapses and hospitalizations, and poor social and vocational functioning (Johnson et al., 2012; Kurtz et al., 2013; Lincoln et al., 2007; Van Baars et al., 2013). However, recent research showed that higher levels of insight do not have exclusively desirable effects, such as better treatment adherence and clinical outcome, but are also linked to more depression, hopelessness, and a greater suicidal tendency as well as lowered self-esteem and quality of life (Cooke et al., 2007; Drake et al., 2004; Lopez-Morinigo et al., 2012; Sharaf et al., 2012). The contradictory empirical findings regarding the correlates and consequences of insight in schizophrenia were described as “insight-paradox” (Lysaker et al., 2007).

Examining the psychological processes underlying this paradox, insight was found to be only associated with negative effects when accompanied by self-stigma (Cavelti et al., 2012a, 2012b; Lysaker et al., 2007; Staring et al., 2009). Self-stigma results from the identification and internalization of negative public stereotypes about mental disorders and includes dysfunctional feelings (e.g. low self-esteem) and behavioural reactions (e.g. social withdrawal) among the affected persons (Corrigan and Watson, 2002). A recent review revealed high prevalence rates of personal stigma among people with schizophrenia: 49.2% reported alienation (shame) as the most common aspect of self-stigma (Gerlinger et al., 2013). Based on previous research, Yanos et al. (2010) proposed a theoretical model how the subjective meaning of having schizophrenia impacts recovery: For example, accepting a definition of oneself as mentally ill and assuming that this means being lifelong handicapped and becoming a socially worthless or even a dangerous person, affect hope and self-esteem, which further influence symptom severity, suicide risk, coping, social interactions and vocational functioning. Thus, insight is not just the acceptance of a single fact (e.g. the illness label or that the illness is caused by a dopamine dysregulation which needs antipsychotic mediation) but the integration of a range of experiences (e.g. having confusing experiences pretending friends to be enemies or the awareness that one is evaluated differently by others after a psychotic episode) into a complex personalized narrative of personal and psychiatric challenges (Lysaker et al., 2013b). If “being insightful” means to accept a diagnosis with detrimental consequences for one’s future, the negative effects found to accompany growing insight may be best described as the result of demoralization. Demoralization is defined as a syndrome of existential distress that can occur in individuals who have a chronic mental illness that threatens integrity of being or of people’s meaning of who they are as engaged subjects in the world (Clarke and Kissane, 2002). In sum, taking the “insight-paradox” into account while fostering recovery seems highly relevant: Interventions targeting insight in order to improve adherence with evidence-based treatments seem indicated to promote symptom remission and rehabilitation of functioning (Lieberman et al., 2002), while demoralization as an “accidental side-effect” of growing insight may undermine these efforts by its detrimental effects on self-concept and motivation (Cavelti et al., 2012a). This notion is in line with the consumer movement who stresses the importance of accepting the diagnosis while keeping or regaining a positive self-concept (e.g. identity transformation from “patienthood” to “personhood”), which enables a meaningful and satisfying life despite the presence of the mental disorder (Davidson et al., 2005; Onken et al., 2007).

Further research is needed to better understand demoralization and its impact on recovery from severe mental illness. Eventually, this could enable us to define more precisely the targets of psychotherapeutic interventions in schizophrenia. In a recent cross-sectional study on outpatients with schizophrenia spectrum disorders we found insight to be related to demoralization and this link to be stronger as self-stigma increased. Moreover, self-stigma was associated with more psychotic symptoms and lower levels of global functioning, while these associations were fully mediated by demoralization (Cavelti et al., 2012b). Building on these findings and the literature referred to above, the aim of the current study was to confirm the supposed process of demoralization impeding recovery from schizophrenia with longitudinal data (see Figure 1). We tested the hypothesis that higher levels of insight at baseline predict higher levels of demoralization after one year. Additionally, this association was expected to be moderated by self-stigma, i.e. the association of insight and demoralization is more pronounced in patients with higher levels of self-stigma. Furthermore, we expected that higher levels of demoralization at baseline would increase positive and negative symptoms and worsen role functioning over time. Finally, we supposed demoralization to mediate the long-term associations of insight and self-stigma with symptoms and functioning.

Please, insert Figure 1 here.

2. Methods

2.1. Participants and procedure

The current study is part of a larger investigation of predictors of service engagement with community mental health services in persons with chronic schizophrenia and contains the longitudinal results based on the same sample as our cross-sectional studies (Beck et al., 2011, 2012; Cavelti et al., 2012a, 2012b; Kvrđic et al., 2013).

Between February 2009 and March 2010 consumers of community mental health services in the region of Basel, Switzerland, between 18 years and 65 years of age and diagnosed with schizophrenia or schizoaffective disorder were recruited. Diagnoses were confirmed by the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders - IV Axis I Disorders (First et al., 1996). Exclusion criteria were a primary diagnosis of alcohol or substance dependency, an organic syndrome or learning disability, inadequate command of German, and homelessness. After a full explanation of the study aims and procedures, participants provided written informed consent. The assessment consisted of an interview and questionnaires for participants and questionnaires for their therapists, administered at baseline (t_b) and at 12-month follow-up (t_f). In order to minimize selection bias by a high refuser rate, participants received a financial compensation of 40 CHF (Swiss Francs) for the baseline and of 60 CHF for the follow-up assessment. The study was approved by the local ethics committee. See Figure 2 for a flowchart of the study procedure.

Please, insert Figure 2 here.

2.2. Measures

We exclusively used measures with established reliability and validity for people with severe mental illness. Measures available only in English were translated into German using the back-translation method (Brislin, 1971).

Insight was assessed using both an observer- and a self-rated measure. The *Scale to assess Unawareness of Mental Disorder* (SUMD; Amador et al., 1993) is a semi-structured interview to evaluate global awareness of having a mental disorder, the achieved effects of medication, and the social consequences of having a mental disorder as well as specific insight into symptoms and their attribution to the mental disorder. These dimensions of insight were rated on a 5-point Likert scale (1="aware" to 5="unaware"), with higher scores indicating poorer awareness. The *Insight Scale* (IS; Birchwood et al., 1994) is a questionnaire to measure insight into psychiatric illness and treatment. Patients respond to eight statements with "I agree", "I disagree", or "I am unsure". A higher total sum score indicates a higher level of insight.

Dysfunctional beliefs about oneself as a person with schizophrenia were assessed by the subscales Self-Concurrence and Self-Esteem Decrement of the *Self-Stigma of Mental Illness Scale* (SSMIS; Corrigan et al., 2006). Each subscale contains 10 items which are rated on a 9-point Likert scale ranging from "1=strongly disagree" to "9=strongly agree". The two subscales Stereotype Awareness and Stereotype Agreement were not considered because being aware of or agreeing with stereotypes can occur purely as a cognitive process without any impact of the self-concept. Instead, only when the person concurs with the stigma and experiences diminished self-esteem can a significant impact on the self be expected (Corrigan et al., 2006). Recent research showed that even the single subscale of Self-Esteem Decrement is a valid approximation of self-stigma (Rüsch et al., 2010).

Recent work demonstrated that the depressive symptoms often seen in schizophrenia are related to patients' perceptions of their illness and might usefully be considered as demoralization (Birchwood et al., 1993; Sharhar et al., 2010; Thomas et al., 2012). Thus, we included both an observer- and self-rated measure to assess depressive symptoms on a continuum with demoralization. The *Calgary Depression Scale for Schizophrenia* (CDSS; Muller et al., 1999) is a semi-structured interview to evaluate depressive symptoms independently of negative symptoms in schizophrenia. Nine items were rated on a 4-point Likert scale (0="absent" to 3="severe"). A higher total sum score indicates a higher level of depression. The *Beck Depression Inventory-Revised* (BDI-II; Kuhner et al., 2007) is a questionnaire consisting of 21 items, each with four statements indicating increasing severity (4-point Likert scale from 0 to 3). A higher total sum score indicates more depressive symptoms. The Emotional Regulation subscale of the *Subjective Well-being under Neuroleptic treatment scale* short-form (SWN; Naber et al., 2001) was added to guarantee that the hallmark of demoralization - hopelessness - was well represented (Clarke and Kissane, 2002). The four items were rated on a 6-point Likert scale (1="not at all" to 6="very much") and added to a total score (item example: "I have no hope for the future").

Positive and negative symptoms common in schizophrenia were assessed by the *Positive and Negative Syndrome Scale* (PANSS; Kay et al., 1987). This semi-structured interview consists of 30 items to measure psychopathological symptoms common in schizophrenia based on a 7-point Likert scale ("1=absent", "7=extreme"). We used the positive and negative syndrome factors identified by Cuesta and Peralta (1995), with higher scores indicating higher levels of psychopathology.

Role functioning was assessed by the *Modified Global Assessment of Functioning* scale (M-GAF; Hall, 1995); a global observer measure of psychological, social, and occupational functioning, covering the range from positive mental health to severe psychopathology. A single score is rated ranging from 1-90, with higher scores indicating a higher level of global functioning.

2.3. Statistical analyses

All statistical analyses were conducted using SPSS version 19.0. At first, to similarly consider self- and observer-ratings, we calculated composite scores, separately for baseline and follow-up data, and, if not normally distributed, applied log transformation. The insight composite scores were built by summing up the z -scores of the reversed total score of the IS and the two SUMD subscales, current awareness and current attribution of symptoms. The baseline insight composite score had to be transformed. Higher composite scores indicate lower levels of insight. The self-stigma composite scores consist of the sum of the two SSMIS subscales, Self-Concurrence and Self-Esteem Decrement, and were both transformed. Higher scores reflect more negative self-beliefs. The demoralization composite scores were calculated by summing up the z -scores of the BDI-II, the CDSS and the Emotional Regulation subscale of the SWN short-form, and were also both transformed. Higher scores indicate being more demoralized.

Afterwards, we tested if the 133 participants who completed the study procedure (completers) differed from the 33 participants who dropped out between the baseline and the follow-up interviews (noncompleters) using one-way ANOVAs. We found no significant differences between completers and noncompleters in positive ($F(1, 164)=3.06, P=.08$), negative ($F(1, 164)=.41, P=.53$), and depressive symptoms ($F(1, 165)=1.56, P=.21$) or in insight (SUMD Current Awareness of Symptoms: $F(1, 164)=.91, P=.34$; SUMD Current Attribution of Symptoms: $F(1, 164)=.36, P=.55$) at study begin. However, at baseline noncompleters ($M=43.66, SD=9.71$) showed a significantly lower level of role functioning than completers ($M=50.34, SD=10.46, F(1, 165)=10.80, P=.00$).

Finally, hierarchical multiple linear regression analyses with the 133 completed datasets were conducted. Beforehand, in order to identify relevant confounders, we tested if the outcome variables at follow-up (demoralization, positive symptoms, negative symptoms and functioning) vary depending on sex, age, diagnosis (schizophrenia / schizoaffective disorder), antipsychotic medication (yes / no) and the additional intake of a mood stabilizer (yes / no) or an antidepressant (yes / no) using one-way ANOVAs. Therefore, the categorical variables were transformed using weighted effects coding, which allows comparing each of the group's means with the grand mean and takes the different group sizes into account (Frazier et al., 2004). We found participants who took a neuroleptic medication to show lower levels of negative symptoms ($M=7.09, SD=2.91$) than those who did not ($M=9.80, SD=3.56$), $F(1, 131)=4.11, P=.05$. Furthermore, the additional intake of an antidepressant was found to be significantly associated with higher levels of demoralization ($M=.77$, respectively, $M=.71, SD=.11$, respectively, $SD=.13, F(1, 131)=8.45, P=.00$) and positive symptoms ($M=4.73$, respectively, $M=3.91, SD=2.36$, respectively, $SD=2.12, F(1, 131)=4.12, P=.00$) as well as lower levels of role functioning ($M=47.07$, respectively, $M=52.54, SD=9.09$, respectively, $SD=9.12, F(1, 131)=10.62, P=.00$). Sex, age, diagnosis and the additional intake of a mood stabilizer had no significant impact on outcome variables. Thus, antipsychotic medication (yes / no) and the additional intake of an antidepressant (yes / no) were considered as confounders in further regression analyses. We used three blocks of predictors, entering one after another. The first block considered the confounding variable, the second block the dependent variable at baseline (t_b) and the third block the predictor variable(s) at baseline (t_b). The contribution of each block to the explained outcome variance was examined by testing the difference in F -scores on significance ($\Delta F, P$). If the block does not significantly contribute to the amount of explained outcome variance, the coefficients should not be further interpreted (Frazier et al., 2004).

2.3.1. Moderator analysis

In order to test the moderator hypothesis, a product term (insight*self-stigma) was created to represent the interactions between the predictor (insight) and the moderator (self-stigma) by multiplying the standardized (i.e. z-scored) forms of these variables assessed at baseline. Before multiplying, a constant term was added to the z-scores in order to guarantee that all z-scores are positive. Running the regression analysis, the standardized predictor and moderator variables assessed at baseline were entered in the third step, followed by the product term in the fourth step (Frazier et al., 2004).

2.3.2. Mediator analysis

In a two-wave longitudinal design, two paths have to be estimated in order to test mediation: First, the path from the predictor variable at baseline (X_b) to the mediator variable at follow-up (M_f) while controlling for the mediator variable at baseline (M_b); and second, the path from the mediator variable at baseline (M_b) to the outcome variable at follow-up (Y_f) while controlling for the outcome variable at baseline (Y_b). The product of the two paths represents an estimation of the mediation (or indirect) effect of X_b on Y_f (Cole and Maxwell, 2003). The significance of the indirect effect was tested by dividing the product of the two paths from X_b to M_f (f) and from M_b to Y_f (g) by the standard error term proposed by Kenny and colleagues (1998) ($\sqrt{g^2 sf^2 + f^2 sg^2 + sf^2 sg^2}$; where f and g are unstandardized regression coefficients and sf and sg are their standard errors). The mediated effect divided by its standard error yields a z-score of the mediated effect. If the z-score is greater than 1.96, the mediation effect is significant at the .05 level. The 95% confidence interval around the estimate of the indirect effect were calculated by the product of the paths f and g $\pm s_{fg}z_{.975}$, where $z_{.975}$ is equal to the constant 1.96 and s_{fg} is the standard error term calculated earlier. Mediation is confirmed, if the confidence interval does not include zero (Frazier et al., 2004).

3. Results

3.1. Sample characteristics

Of the 133 completers, 47 (35.4%) were female. The mean age at study begin was 44.48 years ($SD=11.88$). The majority lived alone ($n=73$; 54.9%) and had neither a stable partnership (of at least three months duration, $n=102$; 76.7%) nor children ($n=98$; 73.7%). On average, they received 12.34 years of education ($SD=2.98$). Most participants were unemployed (neither on the free nor on the protected market) ($n=71$; 53.4%) and received a governmental disability annuity ($n=100$; 75.2%). Eighty-nine participants (66.9%) were diagnosed with schizophrenia and 44 (33.1%) with schizoaffective disorder. On average, participants had been mentally ill since 18.06 years ($SD=12.05$) and treated in the community mental health services since 6.89 years ($SD=6.21$). The majority ($n=128$; 96.2%) received an antipsychotic medication, usually at least one second-generation agent ($n=122$; 91.7%). In addition to the antipsychotic medication, twenty-two participants (16.5%) received a mood stabilizer and 44 participants (33.1%) an antidepressant.

Table 1 contains reliability scores, means and standard deviations of the variables at baseline and follow-up as well as the significances of the mean differences tested by *t*-tests for dependent samples. Notably, while the awareness of symptoms rated by researchers improved, the attribution of symptoms rated by researchers and general insight rated by patients decreased over the study period.

Please, insert Table 1 here.

3.2. One-year predictors of demoralization

We found higher levels of insight at baseline to significantly predict more demoralization at follow-up (see Table 2, Model 1). Self-stigma at baseline was not a significant predictor of demoralization twelve months later (see Model 2). In an additional analysis we tested if the difference of the self-stigma scores at baseline and at follow-up ($M_{it}-M_{ib}$) impacted demoralization at follow-up. Due to the failure to the normality assumption, the log-transformed score was used. We found an increase in self-stigma to be significantly associated with higher levels of demoralization at follow-up (see Model 3). A further regression analysis was run with insight at baseline and the self-stigma difference score as simultaneous predictors of demoralization at follow-up. The significant influence of both predictors (insight: $B(SE)=-.01(.00)$, $\beta=-.16$, $P=.05$; self-stigma difference: $B(SE)=.91(.37)$, $\beta=.20$, $P=.02$) on demoralization at follow-up remained stable ($R^2=.22$, $\Delta R^2=.06$, $\Delta F=5.09$, $P=.01$). To facilitate the interpretation of these results, we repeated the regression analysis separately for patients with an increase ($n=51$; 38.3%) and those with no change or a decrease ($n=82$; 71.7%) in self-stigma during the follow-up period. An increase in self-stigma from baseline to follow-up was significantly associated with higher levels of demoralization at follow-up ($B(SE)=1.75(.85)$, $\beta=.27$, $P=.05$, $R^2=.19$, $\Delta R^2=.07$, $\Delta F=4.22$, $P=.05$), while no change or a decrease in self-stigma scores from baseline to follow-up did not significantly predict demoralization twelve months later ($R^2=.17$, $\Delta R^2=.01$, $\Delta F=.89$, $P=.35$). Finally, to test self-stigma as a moderator of the association between insight and demoralization over one year, we used the self-stigma difference score instead of self-stigma at baseline which was not confirmed as a significant predictor of demoralization at follow-up. The product variable “insight at baseline x self-stigma difference score” failed to significantly impact demoralization at follow-up (see Model 4). Thus, self-stigma did not moderate the association between insight at baseline and demoralization one year later.

Please, insert Table 2 here.

3.3. One-year predictors of clinical outcome

Higher levels of demoralization at baseline were linked to lower levels of role functioning at follow-up (see Table 3, Model 3). The associations of demoralization at baseline with positive and negative symptoms twelve months later were not significant (see Models 1 and 2).

In order to examine the hypothesis that demoralization mediates the associations of insight and self-stigma at baseline with outcome variables at follow-up, we firstly tested the direct impact of insight and self-stigma at baseline on symptoms and role functioning twelve months later. Insight at baseline did neither significantly predict symptom severity (positive symptoms: $R^2=.46$, $\Delta R^2=.00$, $\Delta F=.17$, $P=.68$; negative symptoms: $R^2=.26$, $\Delta R^2=.00$, $\Delta F=.24$, $P=.63$), nor level of role functioning ($R^2=.36$, $\Delta R^2=.00$, $\Delta F=.12$, $P=.73$) at follow-up. Higher levels of self-stigma at baseline were significantly associated with more positive symptoms ($B(SE)=1.96(.73)$, $\beta=.17$, $P=.05$, $R^2=.69$, $\Delta R^2=.03$, $\Delta F=7.14$, $P=.01$) and lower levels of role functioning at follow-up ($B(SE)=-7.12(.344)$, $\beta=-.15$, $P=.04$, $R^2=.38$, $\Delta R^2=.02$, $\Delta F=4.30$, $P=.04$), but were not significantly linked to negative symptoms twelve months later ($R^2=.26$, $\Delta R^2=.01$, $\Delta F=1.07$, $P=.30$). Testing the indirect effects

of insight and self-stigma at baseline on outcome variables at follow-up requires significant associations of the mediator variable (e.g. demoralization) with the outcome variables (e.g. symptoms and role functioning). Since this was exclusively found for role functioning, the mediation analyses were only conducted with role functioning as dependent variable. However, neither the indirect effect from insight to role functioning (z -score=1.37 < 1.96), nor the indirect effect from self-stigma to role functioning (z -score=1.37 < 1.52) were statistically significant, falsifying demoralization as a mediator of the relationship between insight or self-stigma at baseline and role functioning one year later.

Please, insert Table 3 here.

4. Discussion

4.1. Discussion of the results

The aim of the current study was to examine the demoralization process as an obstacle to recovery from schizophrenia. As expected, we found higher levels of insight to predict more demoralization twelve months later. This result confirms our previous cross-sectional work (Cavelti et al., 2012b) and is consistent with findings on insight's negative consequences (Cooke et al., 2007; Drake et al., 2004; Lopez-Morinigo et al., 2012; Sharaf et al., 2012). In previous studies self-stigma was used to resolve the "insight-paradox"; the contradictory finding that insight can be associated with both positive and negative outcomes (Cavelti et al., 2012a, 2012b; Lysaker et al., 2007; Staring et al., 2009). According to this idea, insight is related to negative outcomes when dysfunctional stereotypes of mental illness are internalized and to positive outcomes when they are rejected. Although we found an increase in self-stigma during the observation period to predict more demoralization at follow-up, we failed to confirm self-stigma as a moderator of the insight-demoralization-link. Several reasons may contribute to this unexpected result: Firstly, to the best of our knowledge, this is the first study having examined the associations of insight, self-stigma and aspects of the demoralization syndrome using longitudinal data. Thus, it may be that the moderator effect of self-stigma found in cross-sectional studies does not hold over time. Secondly, there are other studies which also failed to find a moderation effect of self-stigma (Sharaf et al., 2012; Yanos et al., 2008). There is some evidence from cross-sectional research that the relationships of insight, self-stigma and aspects of demoralization may be better explained by a mediation model than a moderator model (Cavelti et al., 2012b; Hasson-Ohayon et al., 2009, 2011). According to a mediation model, insight increases aspects of demoralization by increasing self-stigma. Finally, the insight-demoralization-link could be moderated by other, unconsidered factors than self-stigma, such as the experience of real failure at school or work, and the withdrawal of family and friends.

In our study, insight at baseline did not significantly predict symptoms or role functioning twelve months later. This result is in contrast to other studies which demonstrated the relevance of insight for good clinical outcome (e.g. Kurtz et al., 2013; Van Baars et al., 2013) and may be due to the specific characteristics of our sample. We examined people with a long history of illness and treatment and none (negative symptoms and functioning) or small (positive symptoms) change in clinical parameters over the study period (see Table 1). However, we found higher levels of self-stigma at baseline to lead to more positive symptoms, such as delusions and hallucinations, and poorer role functioning at follow-up. These results confirm our cross-sectional findings (Cavelti et al., 2012b) and are in line with the growing evidence that self-stigma can contribute to the exacerbation of psychotic symptoms and deterioration of daily functioning (Lysaker et al., 2007; Munoz et al.,

2011; Yanos et al., 2008, 2010). According to the social cognitive model of self-stigma (Corrigan and Watson, 2002), internalizing the negative expectations about mental illness may be a source of internal stress which triggers psychotic symptoms and interferes with a person's self-efficacy, eventually undermining motivation for daily performance (Rüsch et al., 2009a, 2013b). For example, individuals may fail to pursue work or an independent living opportunity not (only) because of illness-based disabilities but because of the internalized societal belief that persons with mental illness are not capable of achieving valued social roles and do not deserve a satisfying life. And this may be even true for people without insight into their illness: In our clinical practice, we see patients who do not believe they have schizophrenia, but feel that the diagnostic label makes it difficult for them to pursue their life goals (e.g. a young woman opposed the diagnosis because she feared to be barred from education as a nursery school teacher).

Finally, we found higher levels of demoralization at baseline to also predict poorer role functioning twelve months later, but failed to confirm demoralization as a mediator of the adverse relationship between self-stigma at baseline and role functioning at follow-up. Maybe the detrimental impact of self-stigma on functioning is mediated by other, unconsidered variables, such as symptom severity or self-efficacy (Cavelti et al., 2012b; Hill and Startup, 2013; Kurtz et al., 2013).

4.2. Clinical implications

People with severe mental illness do not suffer only from symptoms and functional impairments, but also from damages on self-concept and future prospects resulting from the negative implications of the illness label and/or the real experience of losses in life (e.g. withdrawal of family and friends, vocational impairment). Our findings highlight the importance of considering both in treatment of schizophrenia: symptoms and functioning as well as the subjective meaning of living with psychosis. If the second aspect is neglected, efforts to promote recovery may be doomed. For example, the treatment of psychotic symptoms by an antipsychotic medication or cognitive-behavioural techniques may fail because the patient does not feel she or he is worthy to try (Corrigan et al., 2009).

Along with psychological models of psychosis (Garety et al., 2001), psychological strategies to cope with symptoms and impairments have been developed during the last years (e.g. cognitive behavioural or acceptance methods for persistent hallucinations and delusions). In contrast, treatment approaches considering the demoralization process are just at their beginnings. Mittal et al. (2012) recently reviewed the literature about interventions to reduce self-stigma among people with mental illness and identified two prominent approaches. The first approach includes psycho-educational and cognitive strategies to alter the stigmatizing beliefs and attitudes of the individual. It regards self-stigma as the result of maladaptive self-statements or cognitive schemata of mental illness which may be altered by normalizing, exploring distressing cognitions about the self, attempting to reframe them as beliefs rather than facts, empathically discussing how one might arrive at such beliefs (but also recognizing their emotional costs), reviewing evidence for and against the beliefs, and trying to find less distressing alternative interpretations. The second approach encourages the acceptance of stigmatizing stereotypes without challenging them (e.g. acceptance and commitment therapy) and enhances skills for coping with self-stigma through improvements in self-esteem, empowerment, and help-seeking behaviour. Recently, Rüsch and colleagues (2013a) developed Coming Out Proud as a manualized peer-led group intervention on weighing the risks and benefits of secrecy versus disclosure in different setting. The program's goal is to enable people with mental illness to decide whether or not to disclose and thus to reduce stigma's negative impact.

Another promising approach to reduce self-stigma is narrative enhancement (Lysaker et al., 2010; Roe et al., 2010). In contrast to the cognitive approach of challenging dysfunctional beliefs about the self and replacing one belief with another, narrative enhancement aims at impoverished senses of self and help people to create a richer personal narrative of who one is in the world in which stigmatizing beliefs are not dominant. Based on the assumption of the onset of a severe mental illness as a disruption in one's autobiography, the final aim is to integrate the experience of the mental illness in one's life story, to fill the void left by negative and damning self-appraisals and to develop a perspective on the future, which is no longer dominated by hopelessness and resignation but includes the opportunity of a meaningful life despite the mental illness. The mutual creation of stories of human lives together with awareness of stigma as unjust might evoke righteous anger and empowerment in life and personal growth. This approach goes in line with the growing amount of psychotherapy researchers who emphasize that all successful psychotherapy entails the articulation, revision, and deconstruction of clients' maladaptive life stories in favour of more life-enhancing alternatives. Because narratives and emotions interact to form meaning and sense of self, the evocation and articulation of emotions is critical to changing life narratives (Agnus, 2012).

4.3. Limitations and conclusion

There are some strengths and limitations to the study which are important to consider. The strengths include the longitudinal design which permits causal inferences, the large sample size, the use of established assessments and the consideration of both self- and observer-rated instruments for insight and indicators of demoralization. The importance of the latter is confirmed by the differences found in insight ratings (see Table 1). However, the following short-comings were identified: First, the present study mixes demoralization and depression, which share symptoms of distress but differ with regard to subjective incompetence and helplessness in the former and anhedonia in the latter (Clarke and Kissane, 2002). However, there is empirical evidence that depressive symptoms seen in people with schizophrenia are related to patients' perceptions of their illness and might usefully be considered as aspects of a demoralization syndrome (Birchwood et al., 1993; Sharhar et al., 2010). For example, Thomas et al. (2012) recently investigated forty persons with a diagnosis of schizophrenia and found that depressive symptoms were correlated with rumination, while controlling for positive and negative symptoms. The content of rumination frequently focused on mental illness and its causes and consequences, in particular social disability and disadvantage. Depressive symptoms were predicted by awareness of the social consequences of mental illness, an effect that was mediated by rumination. Second, the present study rests entirely on deliberate, explicit responses to questions in interviews or questionnaires. However, automatically activated, "implicit" responses may be equally important for the association of insight and negative outcome in schizophrenia (Rüsch et al., 2009b, 2010). Third, this study did not consider other, probably important factors with impact on demoralization in schizophrenia, such as the experience of real losses in life, the traumatic effect of involuntary treatment (Rüsch et al., 2013c) or the depressive effect of symptoms including voices to harm or shame the individual (Trower et al., 2004). Furthermore, this study is also uninformative about factors which may protect from demoralization in schizophrenia. For example, Lysaker et al. (2013a) found that participants diagnosed with schizophrenia with high insight but mild depression demonstrated greater levels of metacognitive mastery and emotion regulation than a group with insight and more severe depression and a group without insight or depression. These differences persisted when controlling for neurocognition and symptom severity and suggest that bolstering metacognitive and social cognitive capacities may have a protective effect as persons

achieve insight. In fact, in a recent study Kukla and colleagues (2013) found that persons with schizophrenia with better metacognitive skills also had greater levels of self-perceived recovery. Thus, the capacity for metacognition as the ability to form complex representations of oneself and others seems important for the construction of a meaningful account of what has happened as a result of the illness and the formulation of a way to adapt to the constraints imposed by schizophrenia and achieve an acceptable quality of life. Finally, because we forced self-stigma to be a predictor of demoralization and clinical outcome, we cannot exclude the possibility that the opposite relationship or a constant day-to-day interaction process is (also) true. For example, patients with more severe symptoms and functional disabilities may consequently feel more demoralized and, therefore, be more vulnerable to self-stigma. Future research should address this alternative hypothesis, for example by using structural equation modelling which allows the simultaneous testing of competing hypotheses.

In sum, in our one-year observational study we found partial support for the demoralization hypothesis in outpatients with schizophrenia spectrum disorders: Insight into illness and an increase in self-stigma independently contributed to a syndrome of demoralization after one year which was associated with poorer functioning, but not with symptoms of psychosis. Furthermore, self-stigma also predicted poorer functioning and more psychotic symptoms. But we failed to demonstrate that demoralization mediates the detrimental effect of self-stigma on clinical outcome. These results support the idea that the poor prognosis attributed to schizophrenia is not only a consequence of psychiatric disability and symptoms of the illness, but is also affected by the ways individuals experience living with psychosis and integrate these experiences into a personalized narrative of the challenges of a serious psychiatric illness as the basis of reacting to and coping with it. Both aspects should be addressed in treatment settings. While different treatment approaches including cognitive, behavioural, accepting, and narrative strategies have been developed, more intervention studies are needed to better understand the differential effects and the underlying mechanisms of change on a psychological and neurobiological level.

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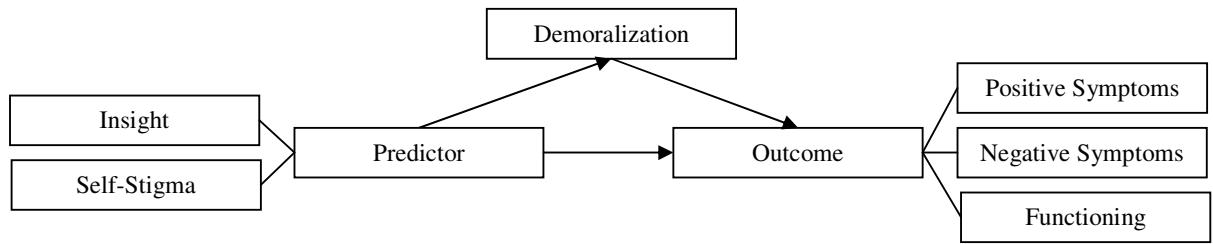


Figure 1. Model of the demoralizing process in schizophrenia: Direct and indirect influences of insight and self-stigma (predictors) on symptoms and functioning (outcomes).

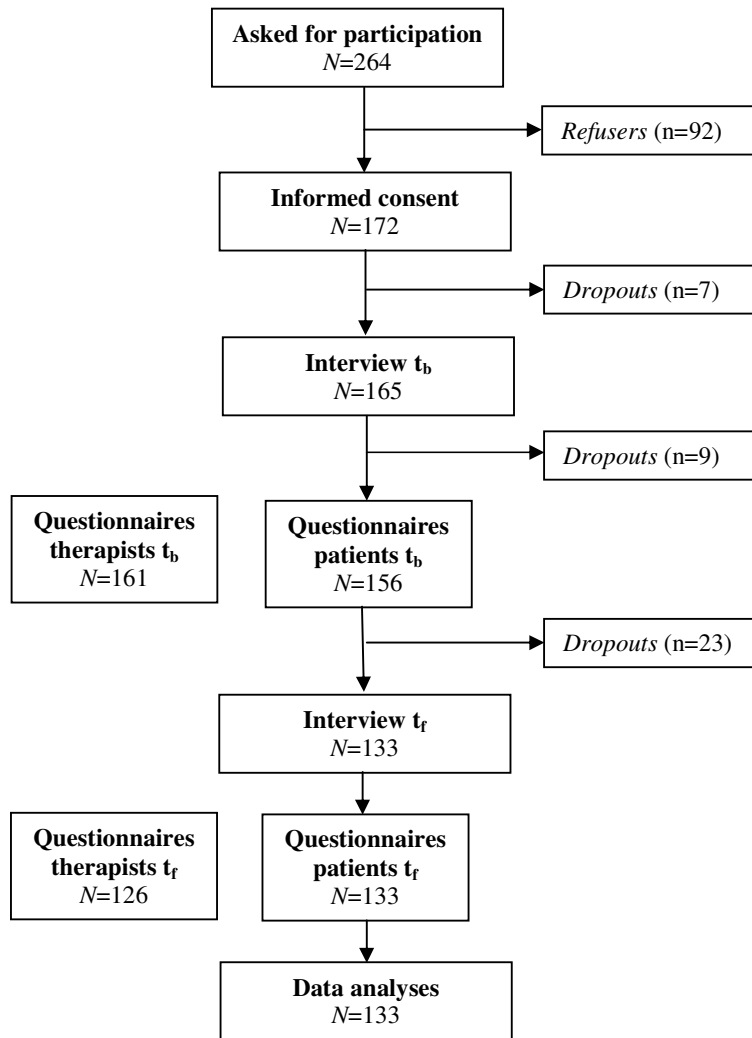


Figure 2. Progress of recruitment and data collection.

Notes. t_b = baseline assessment, t_f = follow-up assessment after twelve months

Table 1. Cronbach's alpha coefficients (α), means (M) and standard deviations (SD) of variables at baseline (t_b) and follow-up (t_f) and the significances of the mean differences (P)

Variable	α_{t_b}	M_{t_b} (SD $_{t_b}$)	α_{t_f}	M_{t_f} (SD $_{t_f}$)	T (df)	P
IS	.71	9.5 (2.42)	.73	9.3 (2.56)	1.04 (132)	.30
SUMD Current Awareness of Symptoms ^a	-	2.16 (1.29)	-	2.61 (1.4)	-3.28 (132)	.00
SUMD Current Attribution of Symptoms ^a	-	2.81 (1.34)	-	2.34 (1.11)	3.86 (132)	.00
BDI-II total score	.90	11.05 (9.61)	.88	9.53 (8.39)	2.18 (132)	.03
CDSS total score	.78	3.47 (3.64)	.66	3.37 (4.13)	.27 (132)	.79
SWN short-form Emotional Regulation	.68	17.33 (4.56)	.56	18.42 (3.99)	-2.75 (132)	.01
SSMIS Self-Concurrence	.74	26.11 (11.2)	.82	25.44 (12.9)	.68 (132)	.50
SSMIS Self-Esteem Decrement	.84	25.46 (13.41)	.85	23.42 (12.98)	1.90 (132)	.06
PANSS Positive Syndrome	.74	4.59 (2.59)	.63	4.18 (2.23)	2.40 (132)	.02
PANSS Negative Syndrome	.69	7.39 (3.14)	.52	7.19 (2.97)	.73 (132)	.46
M-GAF	-	50.35 (10.46)	-	50.73 (9.44)	-.47 (132)	.64

Notes. IS=Insight Scale, SUMD=Scale to assess Unawareness of Mental Disorder, BDI=Beck Depression Inventory-Revised, CDSS=Calgary Depression Scale for Schizophrenia, SWN=Subjective Well-being under Neuroleptic treatment scale, SSMIS=Self-Stigma of Mental Illness Scale, PANSS=Positive And Negative Syndrome Scale, M-GAF=Modified Global Assessment of Functioning.

^areversed scored; higher scores indicate lower levels of insight

Table 2. Hierarchical multiple linear regression analyses with the demoralization composite score at follow-up as dependent variable

Model	Blocks	B (SE)	β	R^2	ΔR^2	ΔF	
1	1	Antidepressant t_b	.04 (.01)	.26**	.07	.07	9.21**
	2	Antidepressant t_b	.04 (.01)	.22**	.15	.09	13.27***
		Demoralization Composite Score t_b	.22 (.06)	.30***			
	3	Antidepressant t_b	.03(.01)	.20*	.18	.03	3.91*
		Demoralization Composite Score t_b	.21 (.06)	.28**			
		Insight Composite Score t_b^1	-.01 (.00)	-.16*			
2	1	Antidepressant t_b	.04 (.01)	.26**	.07	.07	9.21**
	2	Antidepressant t_b	.04 (.01)	.22**	.15	.09	13.27***
		Demoralization Composite Score t_b	.22 (.06)	.30***			
	3	Antidepressant t_b	.04 (.01)	.22**	.17	.02	2.85
		Demoralization Composite Score t_b	.19 (.06)	.26**			
		Selfstigma Composite Score t_b	.08 (.05)	.14			
3	1	Antidepressant t_b	.04 (.01)	.26**	.07	.07	9.21**
	2	Antidepressant t_b	.04 (.01)	.22**	.15	.09	13.27***
		Demoralization Composite Score t_b	.22 (.06)	.30***			
	3	Antidepressant t_b	.03 (.01)	.19*	.19	.04	6.00*
		Demoralization Composite Score t_b	.23 (.06)	.31***			
		Selfstigma Composite Score Δt_f-t_b	.91 (.37)	.20*			
4	1	Antidepressant t_b	.04 (.01)	.26**	.07	.07	9.21**
	2	Antidepressant t_b	.04 (.01)	.22**	.15	.09	13.27***
		Demoralization Composite Score t_b	.22 (.06)	.20***			
		Insight Composite Score t_b^1	-.02 (.01)	-.17*			
	3	Antidepressant t_b	.03(.01)	.20*	.22	.07	5.46**
		Demoralization Composite Score t_b	.22 (.06)	.29***			
		Insight Composite Score t_b^1	-.02 (.01)	-.17*			
		Selfstigma Composite Score Δt_f-t_b	.21 (.09)	.19*			
	4	Antidepressant t_b	.03 (.01)	.21*	.23	.01	1.26
		Demoralization Composite Score t_b	.22 (.06)	.30***			
		Insight Composite Score t_b^1	-.43 (.36)	-3.76			
Selfstigma Composite Score Δt_f-t_b		-.19 (.37)	-.17				
	Product variable	.11 (.10)	3.60				

Notes. t_b =baseline, t_f =follow-up, 1 =a higher score indicates a lower level of insight, * $P<.05$, ** $P<.01$, *** $P<.001$

Table 3. Hierarchical multiple linear regression analyses with the outcome variables at follow-up as dependent variables

Outcome variable	Blocks	B (SE)	β	R^2	ΔR^2	ΔF	
Positive symptoms t_f	1	Antidepressant t_b	.55 (.27)	.17*	.03	.03	4.12*
	2	Antidepressant t_b	.32 (.20)	.10	.46	.43	103.63***
		Positive symptoms t_b	.57 (.06)	.66***			
	3	Antidepressant t_b	.30 (.21)	.10	.46	.00	.73
		Positive symptoms t_b	.56 (.06)	.65***			
		Demoralization Composite Score t_b	.82 (.97)	.06			
Negative symptoms t_f	1	Neuroleptic t_b	-.10 (.04)	-.17**	.03	.03	4.11*
	2	Neuroleptic t_b	-.12 (.04)	-.22**	.25	.22	38.91***
		Negative symptoms t_b	.45 (.07)	.47***			
	3	Neuroleptic t_b	-.13 (.05)	-.21**	.25	.00	.10
		Negative symptoms t_b	.45 (.07)	.48***			
		Demoralization Composite Score t_b	.47 (1.51)	.02			
Functioning t_f	1	Antidepressant t_b	-3.66 (1.12)	-.27**	.08	.08	10.62**
	2	Antidepressant t_b	-2.68 (.95)	-.20**	.36	.28	56.75***
		Functioning t_b	.48 (.06)	.54***			
	3	Antidepressant t_b	-2.51 (.94)	-.19**	.38	.02	4.37*
		Functioning t_b	.46(.06)	.51***			
		Demoralization Composite Score t_b	-9.31 (4.45)	-.15*			

Notes. t_b =baseline, t_f =follow-up, * P <.05, ** P <.01, *** P <.001