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Change in Internalized Stigma and Social Functioning among Persons Diagnosed with Severe Mental Illness

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Abstract

This study examined the relationship between change in internalized stigma and social functioning over time. Thirty-nine individuals with severe mental illness completed measures of self-stigma, social functioning and symptoms at baseline, 4-months, and 7-months. Change in self-stigma was significantly negatively related to change in social functioning, controlling for negative symptoms.

Keywords

Self-stigma; social functioning; negative symptoms

1. Introduction

An accumulating body of evidence supports that internalized stigma, or self-stigma, is associated with compromised outcomes related to recovery from severe mental illness (Yanos et al., 2010a). In a meta-analysis of 45 studies, Livingston and Boyd (2010) found moderate to strong inverse relationships between self-stigma and self-esteem, hope, self-efficacy, social support, and subjective quality of life. A noted limitation of many of the reviewed studies, however, was that they almost exclusively employed cross-sectional designs. In addition, despite its central role in most definitions of recovery, social functioning (which includes vocational functioning and frequency of social contacts) has been rarely examined in relation to self-stigma (and thus was not included in Livingston and Boyd's review). In their conceptual model of how self-stigma affects recovery, Yanos et al. (2010a) hypothesized that internalized stigma would compromise social functioning by leading to poorer vocational outcomes and increased social isolation.

To date, three studies support that self-stigma negatively impacts social functioning. In a cross-sectional study, Muñoz et al. (2011) found a moderate relationship internalized stigma and self-reported social functioning. In another cross-sectional study, Cavelti et al. (In Press) found support for an indirect relationship between self-stigma and social functioning (measured using a rating scale) that was mediated by the relationship between self-stigma and demoralization. Finally, in a prospective study, Yanos et al. (2010b) that found that baseline internalized stigma significantly negatively predicted improvement in vocational

functioning (as measured by a rating scale) at 5 month follow-up, while controlling for positive and negative symptoms.

The present study examined the relationship between changes in internalized stigma and functioning across three time points. It was hypothesized that degree of change in internalized stigma would be associated with degree of change in functioning over time, while controlling for symptoms and demographic variables.

2. Method

2.1. Procedures

2.1.1. Study Context—Data were drawn from a randomized controlled trial examining the effectiveness of targeted psychosocial treatment for internalized stigma in severe mental illness. Findings from the parent study are reported elsewhere (Yanos et al., Under Review). Participants were recruited from two sites: three assertive community treatment teams in New York City and a partial hospital program affiliated with a Veterans Affairs center in Indianapolis, Indiana. Institutional Review Board approval was received for the study and participants provided informed consent.

2.2. Participants

Participants were considered eligible if they demonstrated evidence of elevated internalized stigma, defined as scoring higher than a mean of 1.5 on the Internalized Stigma of Mental Illness Scale (ISMI; Ritsher and Phelan, 2004; see below) on an initial screening, and met criteria for a schizophrenia-spectrum or major mood disorder on the Structured Clinical Interview for DSM-IV (SCID; Spitzer et al., 1993). 38.8% of the screened participants met criteria for elevated internalized stigma.

The 39 participants completing baseline assessments were predominantly (71.8%) male, middle-aged (mean = 47.56 [$SD = 7.3$]), with typically less than high school educations (mean = 11.53 [$SD = 2.85$]), and mean ages of first hospitalization of 24.82 ($SD = 9.16$). Most participants met criteria for schizophrenia (28.2%) or schizoaffective (48.7%) disorders, while a minority met criteria for mood disorders (bipolar I: 12.8%, bipolar II: 7.7%, major depression: 2.6%). Participants were predominantly (69.2%) African-American, with 20.5% European-American, and 10.3% Hispanic.

Assessment schedule—Interviews were conducted at baseline, post-treatment (roughly 4 months after baseline), and 3-months later. Thus, the time frame covered by the study period was roughly 7 months. Participants were paid \$35 for completing the baseline interview and \$25 each for the other interviews.

2.2.1 Training and inter-rater reliability—Training on the assessment battery was provided to clinical interviewers, who demonstrated acceptable levels of inter-rater reliability on rating scales using training videos. After training, inter-rater reliability checks were performed on 10% of the interviews, based on simultaneous rating of interviews (see below).

2.3. Measures

The Mood and Psychosis modules of the SCID (Spitzer et al., 1993) were used at to assess primary diagnosis at baseline. The ISMI (Ritsher and Phelan, 2004) is a 29-item self-report questionnaire that was used to assess self-stigma. Scale scores were calculated as averages to account for missing data, so scores range from 0-3. Previous research provides evidence of good construct validity and reliability, and internal consistency was good across all three

time points (alphas ranged from .75 to .91) in the present study. The Quality of Life Scale (QLS; Heinrichs et al., 1984) is a 21-item rating scale that was used to assess social functioning. The QLS has 4 factors: “Interpersonal Relations,” “Intrapsychic Foundations,” “Instrumental Functioning,” and “Commonplace Objects and Activities.” High to excellent inter-rater reliability was found; intraclass correlations for blind raters observing the same interview were .96 in the Indiana site and .94 in the New York site. The Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987), is a 30-item rating scale of psychiatric symptoms with five factor analytically derived components: Positive Symptoms, Negative Symptoms, Cognitive Symptoms, Hostility, and Emotional Discomfort. High inter-rater reliability was found, with intraclass correlations for blind raters observing the same interview .91 in the New York site and .88 in the Indiana site.

2.4. Analyses

We first explored correlations between internalized stigma, social functioning, symptoms and demographic variables at baseline. Next, we used mixed effects regression analyses (SAS ver. 9) to investigate the relationship between self-stigma, negative symptoms and social functioning (as measured by the QLS) over the three waves of the study. Advantages of mixed effects regression include its ability to tolerate missing data (thus, all participants with at least two observations could be included) and to estimate both fixed and random effects.

3. Results

An examination of correlations between demographic variables, the ISMI, QLS and PANSS subscale scores at baseline ($n = 39$) revealed that QLS total scores were significantly positively related to gender ($r = .365$, $p < .05$, with women showing higher scores), and significantly negatively correlated with PANSS negative symptoms ($r = -.57$, $p < .01$) and ISMI total scores ($r = -.318$, $p < .05$), but were not significantly related to any of the other variables studied.

Most participants (35 out of 39) completed at least one of the later interviews (either post-assessment or follow-up) and could be included in the mixed effects analyses (29 participants had data from all 3 study waves). T-tests were conducted to evaluate whether or not there were any significant differences in baseline scores between participants who did and did not drop out of assessments; the only difference was that there a trend for drop-outs to have lower mean QLS scores ($t = 2.00$, $p = .0524$). This suggests that findings might be biased toward participants with better social functioning. Table 1 presents findings from the mixed effects analysis of the relationship between ISMI total scores, PANSS negative symptoms, and QLS total scores over the three waves of the study. Analyses include data from 99 total observations with the 35 participants who had at least two observations. ISMI scores were allowed to vary randomly across participants. Gender, which was significantly associated with QLS at baseline, was excluded as it was found to not be significantly associated with QLS in the multivariate model and did not alter other findings. As can be seen in Table 1, results indicated that change in ISMI mean scores significantly negatively predicted QLS score over time, even when controlling for negative symptoms. Change in negative symptoms, intercept (baseline ISMI scores), and interview wave were also significantly associated with change in QLS. These results indicate that increased self-stigma predicted lower quality of life over time controlling for the other variables included in the model.

4. Discussion

Findings supported the hypothesis that change in internalized stigma is inversely associated with change in functioning over time, while controlling for symptoms and demographic factors. The finding in the present study is especially compelling because social functioning was measured with a rating scale, whereas internalized stigma was measured by self-report, indicating that the relationship between these two variables is not attributable to “method variance.”

Although the findings neither conclusively indicate that there is a causal relationship between internalized stigma and functioning, nor clarify the direction of the relationship between the two variables, they provide further support to the view that self-stigma and functioning are related and covary over time. Thus, findings support the view of Yanos et al. (2010a) that internalized stigma impacts social functioning, suggesting that interventions targeting internalized stigma might impact functioning.

Some important limitations of the present study should be emphasized. First, the data were obtained from a predominantly male group of participants who initially met criteria for elevated internalized stigma. Thus, findings may not generalize to the broader group of individuals with severe mental illness who are not male and do not exhibit elevated internalized stigma. Second, despite its inclusion of multiple time points, the sample size was quite small, which further limits generalizability and statistical power. Future research should continue to explore the relationship between internalized stigma and social functioning with larger samples, with particular emphasis on how clinical interventions may impact these variables.

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Table 1

Mixed Regression Predicting QLS Total Score Across the 3 Study Waves

Outcome Variable	Estimate	Stand. Error	DF	t-value	P-value
Intercept	4.5969	0.2949	60	15.59	<.0001
Baseline	0.2111	0.1012	60	2.09	0.0412
Post-treatment	-0.00833	0.09416	60	-0.09	0.9298
Follow-up	0				
ISMI	-0.3623	0.1601	38	-2.26	0.0294
PANSS- Negative	-0.08827	0.01122	60	-7.87	<.0001