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# Prevalence of Internalized Stigma among Persons with Severe Mental Illness

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## Abstract

**Purpose—**There is evidence that internalized stigma significantly impacts the lives of people with severe mental illness. Nevertheless, there is little data on the prevalence of clinically significant internalized stigma. This study investigated the current prevalence and demographic correlates of significantly elevated levels of internalized stigma in two samples of people with severe mental illness living in the community.

**Method—**A total of 144 people (79.9% males, 20.1% females) participated, completing a demographic form and the Internalized Stigma of Mental Illness scale.

**Results—**Overall, 36% of the sample had elevated internalized stigma scores using a cutoff criterion. Participants in the middle of the age distribution had the highest scores, and there was a site difference. No other demographic variables studied were related to overall internalized stigma.

**Conclusions—**We conclude that internalized stigma affects a relatively high percentage of people with severe mental illness.

### Keywords

internalized stigma; self-stigma; severe mental illness; prevalence; Internalized Stigma of Mental Illness Scale

## Introduction

A growing body of research has focused on the stigma that people experience after being diagnosed with a mental illness. Stigmatizing attitudes towards mental illness include beliefs that people with mental illness are dangerous, cannot recover, or cannot contribute to society. One consequence of society's stigmatizing attitudes is that people with mental illness often begin to internalize these stigmatizing beliefs, which in turn erodes previously-held positive beliefs about themselves. During this process, a person often loses previously-held identities (e.g., as student, worker, parent) while the stigmatized *illness identity* becomes dominant (Yanos, Roe, & Lysaker, 2010).

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There is evidence that internalized stigma (also termed self-stigma) impacts many domains of the lives of people with severe mental illness. Research suggests that internalized stigma negatively impacts self-esteem (Corrigan, Watson, & Barr, 2006; Lysaker, Tsai, Yanos, & Roe, 2008; Werner, Aviv, & Barak, 2008). There is also evidence that internalized stigma affects variables related to recovery from mental illness, including social relationships (Yanos, Roe, Markus, & Lysaker, 2008), treatment adherence (Fung, Tsang, & Corrigan, 2008), and willingness to seek help (Vogel, Wade, & Hackler, 2007).

Despite evidence that internalized stigma has a negative impact on important outcomes among people with a severe mental illness; few studies have explored its prevalence. The largest study of the prevalence of internalized stigma was reported by Brohan and colleagues (Brohan, Elgie, Sartorius, & Thornicroft, 2010), who conducted survey of people with mental illness in 14 European countries and found that 41% met criteria for elevated internalized stigma. Werner *et al.* (2008) found that 20–33% of persons in an Israeli psychiatric hospital exhibited an elevated level of internalized stigma; while Ritsher and Phelan (2004) reported that 28% of a sample of outpatient veterans with severe mental illness showed elevated levels of internalized stigma. In addition, there have been some suggestions in the literature that internalized stigma might differentially affect racial minorities, particularly African-Americans (e.g., Matthews, Corrigan, Smith, & Aranda, 2006; Rao, Feinglass, & Corrigan, 2007), but further research is necessary to fully understand that possibility. There is a need to investigate further the prevalence of elevated internalized stigma in a more diverse range of settings.

Research measuring internalized stigma has generally failed to employ cutoff scores, making prevalence estimates uncertain. The purpose of the present study was to investigate the current prevalence of significantly elevated levels of internalized stigma in two samples of people with a severe mental illness living in the community. An additional purpose was to explore if demographic characteristics were linked with higher levels of internalized stigma. Gaining information about the scope of this problem can help guide practice by indicating the extent of the need for treatments targeting internalized stigma.

## Methods

### Participants

A total of 144 people (79.9% males, 20.1% females) from treatment programs for people diagnosed with a severe mental illness participated in this study. One sample (70 participants) was recruited from a day hospital treatment program within a Veterans Affairs medical center in Indianapolis, and two samples (74 participants) were recruited from two Assertive Community Treatment programs affiliated with the same agency in New York City. All participants were receiving outpatient psychiatric treatment and met criteria for a severe mental illness as part of their eligibility for these treatment programs. Participants had a mean age of 47.6 [standard deviation = 8.7, range from 28 to 66] and mean years of education of 11.9 (standard deviation = 2.5, range from 4 to 19 years). It was a racially diverse sample with 91 (63.2%) African-American, 38 (26.4%) European-American, 12 (8.3%) Hispanic, 2 (1.4%) Asian, and 1 (.7%) Native American participants. The mean age of first hospitalization was 25.9 (standard deviation = 10.6) and the mean number of past hospitalizations was 10.0 (standard deviation = 14.2). Institutional review board approval was obtained for the study, and all participants provided informed consent prior to participating. All participants were compensated $5 for their participation.

## Measures

**Demographics—**Participants first completed brief questionnaires regarding age, years of education, ethnicity, marital status, age at first hospitalization, number of hospitalizations, and gender.

**Internalized Stigma of Mental Illness Scale—**The Internalized Stigma of Mental Illness Scale is a 29-item self-report scale designed to assess an individual's personal experience of stigma related to mental illness (Ritsher, Otilingam, & Grajales, 2003). Each item is rated on a four-point Likert-type scale (0=strongly disagree; 1=disagree; 2=agree; and 3=strongly agree). Higher total scores are indicative of higher levels of internalized stigma. The Internalized Stigma of Mental Illness Scale can be broken into five subscales: alienation (feelings of being a devaluated member of the community), stereotype endorsement (agreement with negative ideas about people with mental illness), discrimination experience, social withdrawal, and stigma resistance. Previous research has reported high internal consistency ($\alpha$=0.90) and test-retest reliability ($r$=0.92) in a sample of VA psychiatric outpatients (Ritsher *et al*., 2003). In this sample, Chronbach's alpha for the total score was high ($\alpha$=0.92), and reliabilities for the subscales were generally good: Alienation ($\alpha$=0.85), Stereotype Endorsement ($\alpha$=0.76), Discrimination Experience ($\alpha$=0.81), and Social Withdrawal ($\alpha$=0.84). The reliability of the Stigma Resistance scale was low ($\alpha$=0.47), possibly because most items in this scale are reversed-scored (i.e., phrased as positive characteristics).

## Procedures

Interviews were conducted by trained doctoral students in clinical psychology. Participants were approached to participate in the study during a visit to their outpatient psychiatric treatment site, generally while they were in the waiting room. Interviewers asked them if they were interested in completing a 15-minute questionnaire and informed them that they would be compensated $5 for their time. If the person agreed, the interviewer completed a thorough informed consent process. After consent was obtained, participants completed a brief demographics form. Participants were then given the option of filling out the Internalized Stigma of Mental Illness Scale themselves, in which case participants were requested to read the first two items out loud to verify reading ability, or responding as the interviewer read the questionnaire. This procedure allowed people to participate regardless of their level of comfort with reading. Data were collected between March and October 2009.

## Analysis

Based on Brohan *et al*. (2010), we created a cutoff score for the aggregated scale that excluded the stigma resistance subscale, which was excluded as it has been found to lack internal consistency and to be poorly correlated with the other subscales. An average item mean cutoff of 1.5 was selected as this has been used in previous research (Ritsher & Phelan, 2004; Brohan *et al*., 2010). After conducting a mean imputation, the item mean was used to account for missing values. Chi-square and t-test analyses examined whether demographic variables were associated with elevated scale scores. Next, one-way analysis of variance and correlational (Pearson's r) analyses were conducted to examine if demographic variables were associated with mean scores on the total aggregated scale and its subscales. Although the Internalized Stigma of Mental Illness Scale is an ordinal scale, like most psychological instruments, as discussed in Crocker and Algina (1986), there is a consensus that, as long as basic distributional assumptions are met, parametric statistical tests may be used in examining data from ordinal scales. As the Internalized Stigma of Mental Illness

Scale was found to be normally distributed in this sample, these analyses did not employ non-parametric statistical tests.

## Results

The current prevalence of elevated internalized stigma was defined as an item mean score of 1.5 or higher on mean aggregated scale score not including the stigma resistance subscale (this criterion represented the "midpoint" on the 0–3 item scale (Ritsher & Phelan, 2004; Brohan *et al*., 2010). Overall, 36.1% of the sample (52 out of 144 participants) had elevated scores following this criterion. Of the participants in the New York sites, 31.1% (23 out of 74) had elevated scores, while 41.4% (29 out of 70) of the participants in Indiana had elevated scores. Table 1 shows that a larger percentage of women than men had elevated internalized stigma scores (41.4% vs. 34.8%), but this difference was not statistically significant. There were no differences in likelihood of having an elevated score by race/ethnicity. The mean total score was 1.29 (standard deviation = 0.57).

Analyses then investigated whether mean scores varied based on demographic variables. Table 2 shows that most of the demographic variables studied (sex, race/ethnicity, age at first hospitalization, and total number of hospitalizations) were not significantly related to mean scale scores. However, there was evidence of a curvilinear relationship between age and internalized stigma scores, with individuals in the middle of the age distribution scoring highest. To explore this relationship, age was recoded into four categories: youngest–34, 35–44 (early midlife), 45–54 (late midlife), and 55–oldest and the relationship between age groups and mean scores was examined using analysis of variance. With this re-categorized age variable, there was a significant association between age and internalized stigma ($F_{(3,140)} = 4.75$, $p = 0.003$). Specifically the youngest and oldest age categories had lower mean scale scores [1.00 (standard deviation = 0.51) and 1.10 (standard deviation = 0.56), respectively], while the two midlife categories had higher mean scores [1.50 (standard deviation = 0.55) and 1.39 (standard deviation = 0.56) for younger and older midlife participants, respectively]. A multiple comparison test [the Tukey Honestly Significant Difference] revealed that the young midlife participants differed significantly from both the youngest and oldest age groups, while the older midlife participants differed significantly from the young adult participants.

When the subscales were examined, none were found to be significantly related to demographic variables, with the exception of education, which was negatively correlated with stereotype endorsement ($r = -0.256$, $p = 0.002$), indicating that more education was associated with less stereotype endorsement; and number of hospitalizations, which was negatively correlated with stigma resistance ($r = -0.193$, $p = 0.021$), indicating that participants with more past hospitalizations were less likely to endorse positively phrased items.

Despite the minimal associations with demographic variables, mean scale scores varied significantly ($F = 5.24$, $p = 0.02$) by recruitment site (New York versus Indiana), with Indiana participants showing higher mean total scores (1.41 vs. 1.19). The two sites differed significantly in a number of variables that may account for this difference, including age (participants in Indiana tended to be older), education (participants in Indiana had significantly more education), race (participants in Indiana were more likely to be European-American), gender (participants in Indiana were more likely to be male), and age at first hospitalization (participants in Indiana had later ages at first hospitalization). However, as previously noted, only age was significantly related to the mean internalized stigma score. To examine if age differences accounted for differences between the sites, we conducted an

analysis of variance controlling for site and found that age and site had independent significant relationships with the internalized stigma scale score.

## Discussion

This study supports previous literature suggesting that a relatively high percentage of people with severe mental illness experience internalized stigma. Using a cutoff score approach, 36% of participants in two samples showed evidence of currently elevated internalized stigma. Thus, regardless of the approach used, elevated internalized stigma appears to be a clinical issue that affects a substantial number of persons with severe mental illness. The estimation that roughly one third of the sample showed evidence of elevated internalized stigma agrees with prior examinations conducted in different settings (e.g., Ritsher & Phelan, 2004; Werner *et al*., 2008; Brohan *et al*., 2010).

Most demographic variables studied were unrelated to overall internalized stigma. However, investigation of demographic variables found evidence that individuals in the middle of the age distribution (35–54 years) had higher mean scale scores than younger and older individuals. This finding is interesting and has not been previously discussed in the literature. It is possible that individuals in midlife are more likely to be affected by internalized stigma as they consider their personal aspirations, and barriers that may exist toward achieving them; while both younger and older individuals may be less concerned with these issues. Future research is needed to clarify the relationship between age and internalized stigma among people with severe mental illness.

We also found that participants in the Midwestern Veterans Administration Medical Center site had significantly higher mean scale scores (this difference was not accounted for by demographic differences between the samples). This finding may suggest that persons in this type of setting (predominantly male veterans) may be at greater risk for internalized stigma, in contrast with the clients served by the Assertive Community Treatment teams in New York City (predominantly formerly homeless persons). A possible explanation for this difference is the combat experienced by these veterans; however, it is unclear how combat experience and associated Post-Traumatic Stress Disorder would affect internalization of stigma. Another possible explanation for the site difference, which appears to relate more directly to internalization of stigma, is that veterans who develop mental illness have been found to harbor increased concerns of being stigmatized (Hoge, Castro, Messer, McGurk, Cotting, & Koffman, 2004), and elevated negative perceptions of mental health care (Pietrzak, Johnson, Goldstein, Malley, & Southwick, 2009), both of which may contribute to the development of internalized stigma. These attitudes have been proposed as an explanation for why only a small percentage of military professionals seek help for psychiatric difficulties (Hoge *et al*., 2004). Future research should investigate whether veterans are at particular risk for elevated internalized stigma.

A notable limitation of the current analyses is that we did not collect data on diagnosis or symptom severity, and therefore are unable to examine the relationship between these important variables and the likelihood of elevated internalized stigma. The current data were collected as a screening for a larger treatment study, and more extensive assessment of these variables was therefore not conducted. Further research should examine the impact of symptom severity and diagnosis on the likelihood of having elevated internalized stigma. An additional limitation is that the current samples, being predominantly male and non-white, are not representative of the overall population of people severe mental illness. Rather, they may represent specific subgroups of the overall population such as veterans and persons who have been homeless. It should be noted the demographic characteristics of the sample at the New York City sites closely resemble those of individuals who are psychiatrically disabled

and have been homeless in New York City (Metraux, Marcus, & Culhane, 2003). These samples provide prevalence information on outpatients with serious mental illness in the United States, which adds to and is consistent with existing literature suggesting that internalized stigma impacts a substantial percentage of people with severe mental illness.

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**Table 1**

Association of Variables with Elevated Internalized Stigma

| Variable | Elevated Internalized Stigma % (n) | $\chi^2$ (df) | *p*-value |
|---|---|---|---|
| Gender | | | |
| Male | 34.8% (115) | 0.44 (1) | 0.509 |
| Female | 41.4% (29) | | |
| Race | | | |
| African-American | 34.1% (91) | 1.19 (3) | 0.396 |
| European-American | 36.8% (38) | | |
| Hispanic | 50.0% (12) | | |
| Other | 33.3% (3) | | |
| Site | | | |
| New York | 31.1% (74) | 1.67 (1) | 0.196 |
| Indiana | 41.4% (70) | | |

Notes: Elevated internalized stigma is based on an average item mean cutoff of 1.5.

**Table 2**

Association of Variables with Mean Internalized Stigma of Mental Illness Scale

| | n | Mean Standard Deviation | F (df) | *p*-value |
|---|---|---|---|---|
| Gender | | | | |
| Male | 115 | 1.27 (0.60) | 0.920 (1, 142) | 0.340 |
| Female | 29 | 1.39 (0.48) | | |
| Race | | | | |
| African-American | 91 | 1.28 (0.59) | 0.636 (3, 140) | 0.638 |
| European-American | 38 | 1.34 (0.59) | | |
| Hispanic | 12 | 1.35 (0.46) | | |
| Other | 3 | 1.08 (0.61) | | |
| Age | | | | |
| Youngest-34 | 18 | 1.00 (0.51) | 4.75 (3, 140) | 0.003 |
| 35–44 | 25 | 1.50 (0.55) | | |
| 45–54 | 68 | 1.39 (0.56) | | |
| 55–oldest | 33 | 1.10 (0.56) | | |
| Site | | | | |
| New York | 74 | 1.19 (0.54) | 5.24 (1, 142) | 0.024 |
| Indiana | 70 | 1.41 (0.60) | | |
| Education | | | | |
| Less than High School | 52 | 1.39 (0.55) | 1.24 (2, 141) | 0.291 |
| High School | 44 | 1.24 (0.52) | | |
| Greater than High School | 48 | 1.24 (0.64) | | |