Stigma and Discrimination as Correlates of Mental Health Treatment Engagement among Adults with Serious Mental Illness

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Abstract

Objective: The negative impacts of stigma on mental health treatment initiation are well-established, but the relationship of stigma to proactive engagement in mental health treatment (e.g., actively working towards therapy goals) is largely unexamined. This study examined the relationship between mental health treatment engagement and stigma experiences, discrimination experiences, and internalized stigma among adults with serious mental illness. Age, race, gender, and education were tested as moderators of the relationships between stigma-related variables and treatment engagement.

Methods: Data were collected from 167 adults with serious mental illnesses who were receiving services at five psychosocial rehabilitation programs. Treatment engagement was assessed by participants' primary mental health care providers, using the Service Engagement Scale. The relationship between treatment engagement, stigma, and discrimination as well as potential demographic moderators were tested with Pearson's correlations and multiple linear regressions.

Results: Treatment engagement was not correlated with experiences of stigma, experiences of discrimination, or application of stigmatizing beliefs to self. Gender, race, and age were not significant moderators, but education was. Experiences of stigma were associated with greater treatment engagement in those with a higher level of education (p = .007) while application of stigma to one's self was associated with poorer treatment engagement in those with a higher level of education (p = .005).

Conclusions and Implications for Practice: Among individuals with higher levels of education, efforts to prevent internalization of public stigma may be crucial to promote proactive mental health treatment. Replication studies are needed to confirm these findings.

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Adults with serious mental illness (SMI) typically benefit from long-term, recovery-oriented treatment to achieve psychiatric stability and a high quality of life (Kreyenbuhl, Buchanan, Dickerson, & Dixon, 2009). Unfortunately, these individuals may not actively engage in treatment and often stop attending mental health services all together (Bowersox, Saunders, & Berger, 2013; Kreyenbuhl, Nossel, & Dixon, 2009; O'Brien, Fahmy, & Singh, 2009). While people may discontinue treatment for many reasons, including improvement (Katz et al., 2019; Roe et al., 2016), poor treatment engagement and attendance are associated with poorer recovery and quality of life outcomes (Fischer et al., 2008; Kreyenbuhl, Nossel, & Dixon, 2009; Oliver et al., 2010). A better understanding of the factors which facilitate sustained, active engagement in treatment by people in this population is needed.

The effects of mental health stigma are harmful and pervasive. Substantial evidence indicates that mental health-related discrimination has a negative impact on help-seeking behaviors and initial access to mental health care (Clement, Schauman et al., 2015). Less frequently studied is the impact of mental health-related stigma on ongoing active engagement, in recovery-oriented care. Clement, Williams, and colleagues' (2015) systematic review found that the majority of stigma research has focused on attendance of mental health care appointments, i.e. whether one has attended a mental health care session, rather than actual client engagement, i.e. active participation in the activities of mental health treatment such as expressing goals for treatment, completing therapy "homework" outside of sessions, and sharing barriers to recovery.

Mental health-related stigma is a broad umbrella term which can include stigma (i.e. negative beliefs about people with mental illness), discrimination (i.e. denial of the just or legal rights of people with mental illness), and internalized stigma, (i.e. negative stereotypes about people with mental illness which individuals apply to themselves; Corrigan, Druss, & Perlick, 2014). Both external stigma experiences and internalized stigma may be of relevance in terms of treatment engagement; however, this is understudied.

An extremely limited body of literature suggests that among adults with SMI, low self-reported exposure to mental health-related stigma may be associated with better treatment engagement and attendance. In a study of adults with SMI recruited from community mental health centers in the United Kingdom (n=202), mental health discrimination experiences indirectly negatively impacted clients' self-assessment of service engagement via mistrust in mental health services and therapeutic relationships (Clement, Williams et al., 2015). In another study of adults with schizophrenia spectrum and affective disorders recruited from outpatient mental health centers in an urban area in the United States (n=75), low perceived legitimacy of discrimination was related to attendance of at least 2 psychotherapy sessions over a six month follow up period (Rusch et al., 2009). Finally, in a study of adults with schizophrenia recruited from outpatient mental health settings in Hong Kong (n=105), lower levels of internalized stigma were associated with better attendance of and compliance with provider recommendations (Tsang, Fung, & Chung, 2010). These few studies' small

samples, disparate settings, and piecemeal findings make clear that further investigation of ways in which stigma/discrimination experiences and internalized stigma impact treatment engagement, as defined within a recovery framework, is needed.

Previous literature has documented that key demographic characteristics impact mental health related stigma and help-seeking behaviors. Older age, male gender, non-White race, and fewer years of education have been associated with endorsing stigmatizing beliefs (Corrigan & Watson, 2007; Parcesepe & Cabassa, 2013), perceived public stigma, self-stigma, and decreased initiation of mental health services (Wu et al., 2017). In addition, non-White race has been associated with a stronger negative relationship between mental health stigma beliefs and help-seeking behavior, and male gender has been associated with a greater perception of stigma as a barrier to help-seeking (Clement, Schauman et al., 2015). Moreover, age, gender, and race/ethnicity have also been found to moderate the impact of stigma reduction programs such as contact-based education programs (Wong, Collins, et al., 2018). How these demographic characteristics intersect with stigma experiences and self-stigmatizing beliefs to ultimately impact active engagement in treatment among individuals with SMI is unclear.

The present study aimed to examine the relationship between provider-rated treatment engagement and stigma experiences, discrimination experiences, and internalized stigma among adults with SMI recruited from outpatient mental health settings. We hypothesized that all mental health-related stigma measures would be negatively correlated with treatment engagement. In addition, we examined age, race, gender, and education as moderators of the relationships between stigma-related variables and treatment engagement. We hypothesized positive relationships between stigma-related variables and treatment engagement with older age, non-White race, male gender, and fewer years of education.

Methods

This secondary analysis used baseline data from a randomized controlled trial of the Ending Self Stigma (ESS) intervention (Lucksted et al., 2017), a psychoeducation group designed to help adults with SMI reduce the internalization and effects of mental illness stigma. The trial tested ESS in a community-based sample of 268 clients at five Maryland psychosocial rehabilitation programs serving adults diagnosed with schizophrenia, bipolar, recurrent major depressive, schizotypal personality, borderline personality, or other delusional or psychotic disorder and documented functional impairments. All five programs in the study were Maryland certified adult psychiatric rehabilitation programs offering services typical of U.S. psychosocial rehabilitation programs for people with SMI (Farkas & Anthony, 2010). This includes a strengths-based orientation with group, individual, and milieu services that clients use in individualized ways toward improving desired personal and social functioning, and "… a vision of recovery or the achievement of a meaningful life" (Farkas & Anthony, 2010, p. 115). No client self-report of treatment engagement was collected in the original RCT and thus are not available for the present study.

Participants were adults (18 – 70 years old), with serious mental illnesses, attending mental health treatment, who gave written informed consent after the procedures had been fully

explained. People with severe or profound mental retardation were excluded from participation. At each site participants were recruited via flyers, announcements, and provider referral. Multiple waves of 12 to 16 participants were enrolled at each site. A trained research assistant conducted the assessments used in this secondary analysis with each participant, prior to randomization for the parent study. Each participant's primary treatment provider was identified through clinic record review. Of the 268 RCT participants, 62% (n = 167) had a Service Engagement Scale (SES) completed by their provider within 30 days of participant enrollment in the study, had completed the other measures of interest for this research, and thus were included in the present analysis. All procedures were preapproved by the University of Maryland Medical School Institutional Review Board (IRB) and the Sheppard Pratt Health System IRB.

Measures

Demographic information was collected by self-report from research participants.

The <u>Services Engagement Scale</u> (SES; Tait, Birchwood, & Trower, 2002) asks a rehabilitation or clinical staff member familiar with the client to rate the client's active engagement with services over the past 3 months with 14 items rated on a 4-point scale ("not at all or rarely" to "most of the time"). The scale is comprised of four subscales: availability (ex: *The client seems to avoid making appointments*); collaboration (ex: *The client takes an active part in the setting of goals or treatment plans*); help-seeking (ex. *The client seeks help to prevent a crisis*); and treatment adherence (ex: *The client refuses to cooperate with treatment*). The total score can range from 0 to 42 with a score of 11 or higher considered "low" engagement or greater difficulty with engagement. The overall SES has high reliability (alpha = 0.91; present study alpha = .69).

The <u>Wahl Stigma and Discrimination Scale</u> (WSD; Wahl, 1999), is composed of nine items measuring frequency of stigma-related disrespect experiences and 11 items regarding frequency of overt discrimination experiences, rated on a 5-point scale ("never" to "very often"). The stigma experiences subscale score can range from 0–36 and the discrimination subscale from 0–44. The WSD alpha in this study was .81.

The <u>Self-Stigma of Mental Illness Scale</u> (SSMIS; Corrigan, Watson, & Barr, 2006; Watson, Corrigan, Larson, & Sells, 2007) assesses four components of the social-cognitive model of self-stigma: stereotype awareness, stereotype agreement, self-concurrence, self-esteem decrement. Our focus on applying stigmatizing beliefs to oneself led us to use only the self-concurrence subscale (SSMIS–SC) which has previously had a Cronbach's alpha of .81 (Corrigan, Watson, & Barr, 2006) and an alpha of .91 in the present study. The SSMIS–SC consists of 10 items rated on a 9-point Likert scale ("strongly disagree" to "strongly agree') with a possible score ranging from 10–90.

Data Analysis

Pearson's correlations were calculated and multiple linear regression analyses were performed with the SES as the response variable to jointly examine the relationships between stigma/discrimination experiences, self-stigma, and treatment engagement. Subsequently, additional regression analyses were performed to examine interactions

between selected demographic variables, and stigma/discrimination experience and self-stigma. Prior research has found differing levels of self-stigmatizing beliefs among people with SMI based on gender, race, age, and education levels. Therefore, the demographic groups were defined as gender: men (n = 105; 63%) and women (n = 62; 37%); race: white people (n = 90; 54%) and people of color (n = 76; 46%); and education: high school degree or less (n = 131; 78%) and some college or more (n = 36; 22%). Age was analyzed as a continuous variable (range: 18–70; M = 44; SD = 13).

Results

Participants' primary providers rated participants' active engagement in care at an average score of 12.68 (SD = 5.08) on the SES. They reported more experiences of stigma on the WSD (M = 18.35; SD = 5.85) than overt discrimination (M = 10.84; SD = 7.81). The average SSMI self-concurrence score was 24.68 (SD = 13.8). Experiences of stigma, experiences of discrimination, and application of stigmatizing beliefs to self were not significant correlates of treatment engagement in the sample as a whole, although a positive trend was observed between treatment engagement and experiences of discrimination (p = .054; see Table 1).

No significant interactions were found between three of the demographic variables (gender, race, age), and stigma/discrimination experience or self-stigma variables. However, as displayed in Table 2, the interaction of education and experiences of stigma and education and self-stigma were significant indicating that associations between these stigma variables and treatment engagement differed depending on level of education. Participants with some college education or more and higher scores on the WSD stigma subscale, which indicates greater stigma experiences, were rated by their main provider as showing more active engagement in treatment (p = .007). Participants with some college education or more and higher scores on the SSMI self-concurrence subscale, i.e. greater application of stigma ideas to one's self, had lower provider-ratings of engagement in treatment (p = .005). In a separate analysis, there was not a significant difference in treatment engagement between the two education levels. The three-way interaction between stigma experiences, stigma self-application, and education was not significant.

Discussion

While stigma and discrimination are significant negative correlates of treatment initiation there is limited research on their impact on active engagement in ongoing mental health care. The present study addressed this gap. In a sample of 167 people with SMI attending community-based psychosocial rehabilitation programs there was no direct relationship between client self-report of stigma (from others or self/internalized), discrimination experiences, and provider assessment of client active engagement in care. This contrasts with Tsang, Fung, and Chung (2010), who found that higher levels of internalized stigma were associated with poorer compliance with provider treatment recommendations, and Clement, Schauman, and colleagues (2015) who found that mental health discrimination experiences reduced client self-rated engagement in treatment by eroding trust in mental health services and therapeutic relationships.

Thus, our findings may indicate that the negative impacts of stigma and discrimination serve primarily as a barrier to mental health care initiation, such as through anticipatory concerns about experiencing stigma, disrespect, or discrimination associated with mental health care or while sharing mental health symptoms and related experiences with providers. When clients do not encounter additional stigmatizing messages during care and perhaps even encounter anti-stigma messages, stigma's impact on active treatment engagement may be attenuated. Further research is needed to explore this relationship and should include client's perceptions of stigma in the organizational climate where they receive services and their self-ratings of active treatment engagement. If these findings are replicated it may provide valuable information about how anti-stigma education efforts should tailor their messaging and identify key populations to target.

Our additional analysis revealed two significant interactions between stigma and education-level (on treatment provider-rated client engagement in mental health care): For participants with a high level of formal education (some college or more), greater stigmatizing experiences were associated with more active engagement ratings. At the same time higher self-rated self-stigma was associated with less active engagement ratings in the same high-education subsample.

This seeming paradox may be due to important differences between experiencing stigmatization from others and experiencing internalized (self) stigma, and their respective interactions with level of formal education. Among people reporting greater stigma from others, those with higher education may be better able to critically evaluate stigmatizing messages or behaviors and/or may have more information about the benefits of mental health care. Therefore, they may be more likely to view a psychosocial rehabilitation program as a welcome respite or non-stigmatizing environment, facilitating more active engagement. Any of these, or a combination, could account for their being more actively engaged in such programs, and merit further investigation.

Stigma self-concurrence (self-stigma) is a much different phenomenon, comprising internalized negative mental illness stereotypes, plus associated negative feelings such as worthlessness, demoralization, depression, and hopelessness. The higher education / high self-stigma combination may have led psychosocial rehabilitation staff to perceive such clients as less actively engaged via a combination of (1) the de-activating effects of self-stigma beliefs on clients through negative feelings of self-blame, low self-esteem, and poor self-efficacy (Corrigan & Rao, 2012) and (2) staff having higher expectations for clients with a high level of education.

Relatedly, some clients who have received societal validation for educational attainment may therefore perceive societal messages as reliable and thus may perceive negative societal messages about people with mental health disorders as more valid. This perceived message legitimacy (Rüsch, Lieb, Bohus, & Corrigan, 2006) could thus make such people more vulnerable to internalized stigma. For example, individuals with higher levels of education may base more of their self-worth on educational and occupational achievement. Internalizing negative messages about the potential for achievement with a serious mental illness (e.g., beliefs that individuals with SMI cannot attain success) may thus have a more

negative impact on these individuals, contributing to greater hopelessness and decreased engagement in care.

Limitations and Strengths

The real-life context of the original randomized trial meant that study-site providers were sometimes unable to complete SES ratings within the 30-day study window, resulting in more missing data than desirable (n=98; 37%). In addition, other data which might impact treatment engagement such as length of time in treatment or provider demographic data were not available. It is unknown how such data may have impacted study findings.

A strength of this research is its use of provider evaluation of engagement. Provider evaluation of engagement is less frequently utilized in research because it is generally harder to obtain than client self-report data, but it provides unique insight since providers see many clients and are thus able to observe a range of client engagement levels. However, it does only represent the views of one half of the therapeutic dyad and has its own potential reporting biases. For example, previous research has found that providers in the United States believe that African American patients, compared to White patients, are less likely to adhere to treatment or be personally responsible for their health (Khosla, Perry, Moss-Racusin, Burke, & Dovidio, 2018). The use of client self-report of engagement is valuable in order to understand clients' lived experience of treatment and engagement in treatment and to conduct research in a person-centered manner. Future research should collect both provider and client assessments of client engagement in treatment.

Conclusions

Further research is needed to describe the relationship between stigma and discrimination and treatment engagement, particularly a broader definition of engagement which includes not only initiation and attendance, but proactive engagement in treatment, as assessed by both clients and providers. Delineating the relationship between stigma and discrimination, potential moderators, and the various facets of treatment engagement will provide valuable guidance for mental health researchers and providers seeking to provide targeted, tailored anti-stigma interventions.

Acknowledgments

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Impact and Implications

This study found that stigma-related experiences affected treatment engagement in people with higher levels of education. For these people, experiences of stigma were related to higher engagement, and applying stigmatizing beliefs to oneself (self-stigma) was related to lower engagement. This indicates that preventing or treating self-stigma among individuals in mental health treatment may be important in promoting active engagement for some individuals.

Table 1

Pearson Correlations between Stigma and Engagement Scores

	1	2	3	4
1. SES[a]	-			
2. WSD discrimination	.15	-		
3. WSD stigma	−.067	.409[***]	-	
4. SSMI self-concurrence	.09	.209[**]	.182[*]	-

[*] p<.05

[**] p<.01

[***] p<.001

Table 2

Education Subgroup Regression for Stigma Experiences and Self-Stigma

	B	SE B	t Value
Intercept	12.78	.70	18.23
SSMI self-concurrence	−0.92	.78	−1.18
WSD stigma	.07	.54	.12
Edu 13+	3.17	1.87	1.7
SSMI self-concurrence *WSD stigma	.81	.55	1.47
SSMI self-concurrence *Edu 13+	3.09	1.09	2.84**
WSD stigma *Edu 13+	−4.05	1.49	−2.72**

*
p<.05

**
p<.01

***
p<.001

Note: Higher scores on the SES indicate greater difficulty with engagement.