Stigma, agency and recovery amongst people with severe mental illness

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ABSTRACT

Evidence suggests that people with a severe mental illness still suffer high levels of stigma and discrimination. However little is known about how people with a severe mental illness manage such stigma. As such, the overall aim of this study is to document and analyze behavioral and psychological strategies of stigma management and control in a sample of people in recovery from a severe mental illness. To meet this aim, we conducted a five-year (2008–2012) qualitative longitudinal study in Washington D.C. Participants were recruited from small-scale congregate housing units ('recovery communities') for people in recovery, provided by a public mental health agency. We conducted regular focus groups at these communities, augmented by in-depth participant observation. Analysis was propelled by the grounded theory approach. A key finding of this study is that stigma and discrimination were not perceived as commonly *experienced* problems by participants. Instead, stigma and discrimination were perceived as omnipresent *potential* problems to which participants remained eternally vigilant, taking various preventive measures. Most notable among these measures was a concerted and self-conscious effort to behave and look 'normal'; through dress, appearance, conduct and demeanor. In this endeavor, participants possessed and deployed a considered degree of agency to prevent, avoid or preempt stigma and discrimination. These efforts appeared to have a strong semiotic dimension, as participants reported their developing 'normality' (and increased agentic power) was tangible proof of their ongoing recovery. Participants also routinely discussed severe mental illness in normative terms, noting its similarity to physical illnesses such as diabetes, or to generic mental health problems experienced by all. These behavioral and psychological strategies of normalization appeared to be consolidated within the recovery communities, which provided physical shelter and highly-valued peer support. This fostered participants' ability to face and embrace the outside world with confidence, pride and dignity.

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1. Introduction

The word 'stigma' originated as a noun in ancient Greek, which literally meant a 'brand' or 'mark'. Historians have noted that in ancient Greece, slaves were often branded with the letter S, which marked them out in perpetuity from the rest of society (Simon, 1992). The concept of stigma has since entered the social sciences, mainly through the seminal work of scholars such as Goffman (1963) and Foucault (1995). Goffman (1963, p3) defined stigma as 'an attribute that is deeply discrediting…turning a whole and usual person to a tainted and discounted one'. He further noted that stigma can be divided into that which is *discredited*- this being an obvious mark easily perceived by an observer, or *discreditable*- this being a secret stigma not readily apparent to an observer. Goffman states that, once noted by an observer, stigma can mark out the bearer for undue scrutiny, criticism, ridicule, mockery and discrimination. In a similar vein, Foucault (1995) argues that the stigmatized are often the focus of precautionary surveillance from both state authorities and the general public. This 'disciplinary gaze' can be internalized by the bearer of the stigma, leading to self-doubt, shame and guilt (Schulze and Angermeyer, 2003).

Stigma is a secondary correlate of many illnesses, including leprosy, HIV/AIDS and mental illness. Indeed a massive body of

research indicates that people with a mental illness suffer high levels of stigmatization, which often leads to discrimination and marginalization (Thornicroft et al., 2010; Corrigan et al.,, 2004). This is especially the case for people with a Severe Mental Illness (SMI) such as schizophrenia. For example, people with SMI frequently have difficulty obtaining gainful employment or finding suitable accommodation (Stuart, 2008; Corrigan et al., 2006). Many attempt to conceal their SMI from colleagues, friends or even family, for fear of being shunned and stigmatized (Link et al., 1999; Thornicroft, 2007). These forms of discrimination and ongoing marginalization are sometimes known as enacted or external stigma. This stigma is often internalized with negative consequences for subjective well-being. This is sometimes known as felt or internal stigma (Scambler and Hopkins, 1986).

Research has shown that some factors can counteract the negative impact of stigma and promote recovery. At the societal level, anti-discrimination legislation, as well as targeted anti-stigma campaigns can reduce levels of enacted stigma (Stuart, 2006; Pinfold et al., 2005). At the treatment level, some research suggests that mental health services that focus on recovery, empowerment and peer support can reduce levels of felt stigma (e.g. Corrigan, 2002; Jensen and Wadkins, 2007; Verhaeghe et al., 2008).

That said, research has shown the persistence of negative attitudes towards people with SMI among the general public (Read et al., 2006; Phelan, 2005). Numerous studies suggest that levels of stigma have not diminished over time (e.g. Pescosolido et al., 2010; Phelan et al., 2000; Angermeyer and Matschinger, 2005). Indeed, in a systematic review of this literature assessing studies from 1950 to 2011, Schomerus et al. (2012) worryingly conclude that "no changes, or even changes to the worse, were observed regarding attitudes towards people with mental illness" (p440).

Qualitative research is well suited to exploring the subjective impact of stigma, being able to access the lived day-to-day experience of individuals. Only a few notable qualitative studies have shed light on the impact of stigma. Dinos et al. (2004) conducted narrative interviews with people with mental illness, finding that stigma was a pervasive concern, manifesting itself regularly in patronizing attitudes as well as overt discrimination. Similarly, Schulze and Angermeyer (2003) conducted focus groups with people with schizophrenia, finding that stigma was frequently felt to be present in interpersonal interactions. Participants also believed that stigma limited their access to valued social roles, leading to further discrimination.

These studies have successfully described the nature and extent of stigma from a subjective perspective. While useful, this description begs further questions. What do people with SMI (as active agents) do *in reaction to* stigma? In other words, what strategies and orientations do people with SMI engage in to manage, lessen, avoid or confront stigma? Is stigma associated with SMI an indelible badge of shame – what Goffman calls discredited stigma? Or is it something that can be actively concealed or obscured, what Goffman calls discreditable stigma?

In order to explore the above questions, we conducted a longitudinal qualitative study of people diagnosed with SMI to explore their psychological and behavioral reactions to stigma. As such, the overall aim of this study is to document and analyze strategies of management and control of stigma in a sample of people in recovery from SMI.

2. Methods

This paper reports findings from a larger study entitled 'Creating Communities'. This study evolved from a desire to understand the role that 'recovery communities' could play in the recovery of individuals with SMI. Recovery communities in this sense refer to small scale congregate housing units of between 6 and 18 apartments inhabited by people in recovery from SMI, who have also made an active commitment to abstinence from substance use. Residents are given their own self-contained apartment with no live-in professional support; the idea being that peer support provided in the communities will assist in recovery. Residents are also offered participation (by choice) in three psychosocial evidence – based practices (i) supported employment (Becker and Drake, 2003); (ii) Illness Management and Recovery (Mueser et al., 2002) and (iii) Integrated Dual Diagnosis Treatment (Drake et al., 1998). They also receive intense case management services and careful medication management from a psychiatrist. All the above services are provided by a single community mental health agency. The recovery communities are concentrated in the overwhelmingly African American NE and SE quadrants of Washington DC. Recovery communities are a relatively new intervention, expanding in the District of Columbia from three such communities in 2005 to twelve in 2013. The current research was funded in part to test the feasibility and effectiveness of these communities in fostering recovery.

This longitudinal study utilized the grounded theory approach to examine the experience of recovery among people living in these communities. As demanded by grounded theory, rounds of data collection were followed by interim analysis, hypothesis generation, and hypothesis testing in subsequent data collection (Glaser and Strauss, 1967). As such, focus groups were held every four months over a five year period (2008–2012) to elicit perspectives on recovery. The study began with only three recovery communities, but had expanded to eight by its termination. Focus groups were augmented by in-depth participant observation at the three original communities by the first author.

2.1. Participants

All participants in this study had a diagnosis of SMI: either schizophrenia, bi-polar disorder, major depression or schizo-affective disorder. The vast majority had this diagnosis for over 5 years, with many having spent time hospitalized for their illness. All the participants were recovery community residents, largely women (75%) and African-American (83%). The average age of the residents was 47 years old. All the residents had experienced periods of homelessness (this being a criterion of entry into the recovery community) and over 80% also had a diagnosis of substance use disorder. Many of the participants had a history of sexual abuse and victimization, and most lived on a low income.

2.2. Procedures

The present study began in 2008, however the first author had conducted other research at the recovery communities from 2005 to 2008. As such, he had established a personal and trusting relationship with many of the residents which facilitated recruitment and the building of rapport. At the commencement of this study (2008), all residents were informed of the study design, including the regular focus groups, led by the first author. Case managers who worked at the communities would announce the upcoming focus group in good time. Most residents participated repeatedly in multiple groups over time. As such, the results tend to represent the perspectives of people with long-term tenure in the recovery community. All groups were held in residents' homes or common areas within the recovery community building. Focus groups typically included about six to twelve residents, although exact numbers were difficult to ascertain as many participants came and