

DSM-V and the stigma of mental illness

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Abstract

Stigma associated with mental illness has been shown to have devastating effects on the lives of people with psychiatric disorders, their families, and those who care for them. In the current article, the relationship between diagnostic labels and stigma is examined in the context of the forthcoming DSM-V. Three types of negative outcomes are reviewed in detail – *public stigma*, *self-stigma*, and *label avoidance*. The article illustrates how a clinical diagnosis may exacerbate these forms of stigma through socio-cognitive processes of *groupness*, *homogeneity*, and *stability*. Initial draft revisions recently proposed by the DSM-V work groups are presented, and their possible future implications for stigma associated with mental illness are discussed.

Keywords: *Stigma, diagnosis, DSM-V, mental illness, labeling*

Introduction

Understanding labels – “that person is a schizophrenic” – is fundamental to understanding the stigma of mental illness. Diagnosis is an important social force in the formation of these labels. The series of papers in the current edition provide several different perspectives on DSM-V. Here we examine the relationship between diagnostic labels and stigma. Later, we consider some suggested innovations in DSM-V and the possible effects they may have on stigma. First, though, we review the impact of stigma on people with serious mental illness. To do this, we describe the various forms and foci of stigma, ideas that have largely developed out of social psychology and its rich tradition in social cognition. Social psychological processes are then used to directly consider diagnosis’ impact on stigma. Finally, we examine some conceptual and practical changes that are currently being examined as suggested modifications in DSM-V, and consider how these changes might affect the diagnosis stigma interaction.

The impact of stigma

Psychiatric disorders have catastrophic effect on the lives of people with these disorders because of their associated distress and disability. Many advocates and scientists also believe the stigma of these disorders wreaks havoc on many lives. Goffman (1963) originally adopted the term stigma from the Greeks who used it to represent bodily signs indicating something bad about the moral character of the bearer marked with the stigma.

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When applied to individuals with mental illness, this kind of moral imputation has egregious effects on a number of levels, what we have called *public stigma*, *self-stigma*, and *label avoidance* (Corrigan et al., 2004; Corrigan & Watson, 2002).

Public stigma is the phenomenon of large social groups endorsing stereotypes about, and subsequently acting against, a stigmatized group: in this case, people with mental illness. *Self-stigma* is the loss of self-esteem and self-efficacy that occurs when people internalize *public stigma*. *Label avoidance* is a third example of stigma: people do not seek out or participate in mental health services in order to avoid the egregious impact of a stigmatizing label.

Public stigma is conceptualized as a staged process. In the first stage, the general public infers mental illness from explicit cues: psychiatric symptoms, social-skills deficits, physical appearance, and common diagnostic labels (Corrigan, 2000; Penn & Martin, 1998). These stigmatizing cues often elicit stereotypes, knowledge structures that the general public or individual with mental illness learn about a marked social group (Corrigan, 2007; Krueger, 1996; Lauber & Rossler, 2007). Commonly held stereotypes about people with mental illness include violence (people with mental illness are dangerous), incompetence (they are incapable of independent living or real work), and blame (because of weak character, they are responsible for the onset and continuation of their disorders) (Corrigan et al., 2000; Link et al., 1999). Knowledge of a set of stereotypes however, does not necessarily constitute agreement with them (Devine, 1989; Jussim et al., 1995). Therefore, the outcomes of *public stigma* are most damaging only when people who are prejudiced endorse negative stereotypes (“People with mental illness are violent and incompetent”) and generate negative emotional reactions as a result (“I am afraid of them”) (Corrigan et al., 2009; Devine, 1995). In contrast to stereotypes, which are beliefs, prejudicial attitudes involve an evaluative (generally negative) component (Allport, 1954; Eagly & Chaiken, 1993). Prejudice is a cognitive and affective response that leads to discrimination, a behavioral reaction (Crocker et al., 1998). Discriminatory behavior constitutes a negative action against the out-group, which may manifest as avoidance, not associating with people from the out-group, or loss of opportunities or treatments that would promote a person’s goals.

Public stigma harms people who are mentally ill in several ways. Stereotype, prejudice, and discrimination can rob people labeled mentally ill of important life opportunities that are essential for achieving their life goals. Studies have shown that public stereotypes and prejudice about mental illness have a deleterious impact on obtaining and keeping good jobs (Baldwin & Johnson, 2004; Link, 1987; Scheid, 2005; Stuart, 2006; Wahl, 1999) and leasing safe housing (Aviram & Segal, 1973; Corrigan et al., 2003; Ozmen et al., 2004; Wahl, 1999). It appears employers avoid workers with mental illness by not hiring them. Landlords “protect” tenants from people with mental illness by not renting to them.

The negative impact of *self-stigma* can be just as great. Prior to the onset of mental illness most people are aware of the culturally endorsed stigma associated with mental illness. Upon receiving a diagnosis, the beliefs associated with stigma are activated, affecting one’s sense of self. Living in a culture steeped in stigmatizing images, persons with mental illness may accept these notions and suffer diminished self-esteem (Corrigan et al., 1999; Rosenberg, 1965), self-efficacy (Bandura, 1989), and confidence in their future (Corrigan, 1998; Holmes & River, 1998). Research shows that people with mental illness often internalize stigmatizing ideas that are widely endorsed within society and believe that they are less valued because of their psychiatric disorder (Link, 1987; Link & Phelan, 2001). Persons who agree with prejudice concur with the stereotype; “That’s right; I am weak and

unable to care for myself!” Self-prejudice leads to negative emotional reactions; prominent among these is low self-esteem and low self-efficacy (Link et al., 2001; Markowitz, 1998). Low self-efficacy and poor self-esteem have been shown to be associated with failing to pursue work or independent living opportunities at which people with mental illness might otherwise succeed (Link, 1982, 1987).

The negative impact of *self-stigma* on self-esteem and self-efficacy may result in a “why try” effect in individuals with mental illness (Corrigan et al., 2009). The person may avoid situations where he/she expects to feel publicly disrespected. Behavioral consequences in the “why try” model exceed notions such as social avoidance. People who apply stigma to themselves may feel unworthy or unable to tackle the exigencies of specific life goals. One might think that beliefs like these arise because the person indeed lacks basic social and instrumental skills to accomplish a specific aspiration. However, lack of confidence may reflect doubts raised by defining one’s self in terms of specific stereotypes. A person who has internalized stereotypes such as “the mentally ill have no worth because they have nothing to offer and are only drains on society” will struggle to maintain a positive self-concept (Corrigan et al., 2009).

Research has suggested that many people engage in *label avoidance*, that is, they choose not to pursue mental health services because they do not want to be deemed a “mental patient” or suffer the prejudice and discrimination that the label entails. For example, results from the Yale arm of the Epidemiological Catchment Area data showed that negative attitudes about mental health inhibit service use in those at risk of a psychiatric disorder (Leaf et al., 1987). Findings from the National Comorbidity Survey identified stigmatizing beliefs that might sway people from treatment (Kessler et al., 2001). These included concerns about what others might think and the desire to solve one’s own problems. Sirey et al. (2001) found that endorsing stigma predicted whether adults were compliant with their antidepressant medication regimen 3 months later. Furthermore, research has suggested that people with concealable stigmas (people who are gay, of minority faith-based communities, or with mental illness) may decide to avoid harm by hiding their stigma and staying in the closet (Corrigan & Matthews, 2003). These individuals may opt to avoid the stigma all together by denying their group status and by not seeking the institutions that mark them (i.e. mental health care). This kind of *label avoidance* is perhaps the most significant way in which stigma impedes care seeking.

Diagnosis and stigma

Mental health professionals use diagnosis and nosology to describe individuals with mental illness. As outlined in the most widely used systems such as the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., DSM-IV; APA, 1994), diagnosis is fundamentally a classification enterprise. Thus, diagnosis assumes that all members of a group are relatively homogeneous and that all groups are distinguished by definable boundaries (APA, 2000). Diagnostic classification serves several goals. It neatly corresponds with a dominant cognitive efficiency used by humans to understand a large amount of information (First et al., 1997; Rosch & Mueller, 1978). It provides clinicians with an efficient means for describing their patients that includes not only presentation of symptoms but also indicates expected course and prognosis, associations with laboratory tests, patterns of family psychiatric history (Robins & Guze, 1970), etiology, and treatment response. Despite these benefits, mental health professionals also recognize pitfalls to diagnosis and categorization (APA, 2000); one of these pitfalls is their impact on stigma. Three processes – *groupness*, *homogeneity*, and *stability* – illustrate how diagnosis may exacerbate stigma.

Groupness is the degree to which a collection of people is perceived as a unified or meaningful entity (Campbell, 1958; Hamilton & Sherman, 1996). Groups have a sense of differentness from the population, based on a salient and socially important characteristic. Eye color and foot size are generally not qualities that lead to meaningful groups, whereas skin color and bizarre behavior are. Diagnosis distinguishes people with mental illness from the general population and adds to the salience of their *groupness* (Link & Phelan, 2001). Although the collection of people with mental illness has a sense of *groupness* even without diagnostic systems, research has shown a nonspecific prejudice against people who are mentally ill compared with people with other health conditions (Corrigan et al., 2000; Weiner et al., 1988). In addition, diagnostic labels such as schizophrenia and psychosis seem to worsen the level of prejudice (Phelan et al., 2000).

Groupness and stereotypes have a bidirectional causal relationship (Crawford et al., 2002; Yzerbyt et al., 1997). Stereotypes only make sense in terms of a meaningful group of people; the public fails to regularly recall stereotypes for amorphous classes. Hence, diagnoses that increase the sense of *groupness* will strengthen the stereotypes associated with mental illness. Conversely, stereotypes are the negative attributes that provide description to the group (Link & Phelan, 2001). Perceptions of *groupness* do not endure when not associated with attributes that describe them.

At this stage, one might ask whether diagnoses make the stereotypes worse or merely highlight meaningful differences that, in fact, occur because of abnormal psychiatric symptoms? In an effort to resolve differences between labeling theory and actual symptoms, Link (1987) conducted a study in which label and aberrant behavior were independently manipulated in a series of vignettes. Results indicated that members of the general public were likely to stigmatize a person labeled mentally ill even in the absence of any aberrant behavior. Subsequent studies have replicated this finding (Link et al., 1987; Link et al., 1999). Link and coworkers (1987, 1999) posed a modified labeling theory to make sense of the diverse literature, concluding that psychiatric labels are associated with negative societal reactions that exacerbate the course of the person's disorder.

Members of stereotyped out-groups are seen as more *homogeneous* than in-groups (Ashton & Esses, 1999; Rothbart et al., 1997; Tajfel, 1978). This leads to an overgeneralization error; namely, that all members of a group are expected to manifest the characteristics attributed to that group. All people diagnosed with schizophrenia are "expected" to hallucinate and all people with depression are assumed to be suicidal. Diagnosticians have noted this concern when advising clinicians in the text revision of the DSM-IV (APA, 2000) to use clinical judgment and flexibility to ensure that the description of an individual case is not voiced solely in terms of the diagnostic criteria: "There is no assumption that all individuals described as having the same mental disorders are alike in all important ways" (p. xxxi).

There is evidence that diagnosticians are writing in a less stigmatizing tone now. The Institute of Medicine (2001) provided a comprehensive summary on the international state of neurological, psychiatric, and developmental disorders. This text is remarkable in the ways in which people with specific disorders were portrayed: not in terms of specific characteristics that automatically represent them because of diagnosis but instead as a range of dimensional probabilities. The Institute of Medicine text did a marvelous job of describing diagnoses while respecting the heterogeneity of individuals with that diagnosis. Nevertheless, there continue to be contemporary examples of professional texts that equate diagnosis with person.

Stereotypic descriptions about stigmatized groups often include a component of *stability*; namely, the traits that describe a group are believed to remain relatively static and

unchanging (Anderson, 1991; Kashima, 2000). This quality of stereotypes can be especially problematic for health conditions because it suggests that people with specific disorders do not recover from those disorders. This can lead to unnecessarily pessimistic attitudes about prognosis and the treatment efficacy. Research has suggested that *stability* attributions can be especially troublesome for people with psychiatric diagnoses. Studies have shown that people with psychiatric disorders are viewed by the public as less likely to overcome their disorders than those with physical illnesses (Corrigan et al., 2000; Weiner et al., 1988). This coincides with an especially egregious myth about people with mental illness, especially those with serious psychotic disorders; namely, that people with mental illness do not recover (Harding & Zahniser, 1994). This kind of myth leads to a general pessimism that can undermine people's sense of self-esteem and self-efficacy, which, in turn, prevents many people with psychiatric disorders from pursuing their life goals (Corrigan, 2006).

DSM-V and stigma

The American Psychiatric Association recently made public initial draft revisions proposed by the DSM-V work groups. The draft was presented on the APA website with a message from the DSM-V task force leadership asking for the public's input and feedback about the suggested modifications (APA, 2010a). This is the first time that APA opens its doors to broad public review of the process and considerations that go into revisions of their most widely used diagnostic system, and giving mental health professionals, researchers, and persons/family members affected by mental illness the opportunity to provide feedback and input. It is a commendable initiative and undoubtedly reflects APA's response to the requests of increasingly proactive advocacy groups for greater transparency and openness in the conceptualization of mental illness, as well as cognizance of the need to understand mental illness and the effects of diagnoses from the perspective of those impacted by them the most. Whether and how professional and public input will impact the final version of the DSM-V scheduled for release in 2013 remains to be seen.

We have identified a number of elements in the interim draft of the DSM-V that we view as especially relevant to stigma in the context of the processes discussed in the previous sections. We present specific revisions suggested by the task force and briefly discuss them from the framework of mental illness stigma.

Dimensional approaches to nosology

Widiger and Samuel (2005), and many others, have discussed the boundary and excessive comorbidity problems that occur as the result of the DSM system taking a strictly categorical approach to nosology. Discrete categories emphasize the perception of *groupness*, *homogeneity*, and *stability*. The DSM-V Nomenclature Work Group recommended "that consideration be given to advantages and disadvantages of basing part or all of DSM-V on dimensions rather than categories" (Rounsaville et al., 2002, p. 12). A dimensional approach to diagnosis (e.g. Widiger & Samuel, 2005) changes the question of diagnosis from "present or absent" to individual differences on one or more dimensions of pathology. Such a system would reduce the discrete *groupness* of individuals and could highlight the instability over time of the dimensional diagnosis "score(s)".

The Personality and Personality Disorders Work Group proposed reformulation of the approach to the assessment and diagnosis of personality psychopathology, including a revised general definition of personality disorder, a limited set of personality disorder

types, and the provision for clinicians to rate dimensions of personality trait domains and overall severity of personality dysfunction (APA, 2010b). The proposed personality disorder section is appropriately more dimensional and nuanced. If clinicians attend to these components of the criteria in addition to the final diagnosis, these changes have the potential to increase perceptions of heterogeneity and the continuum of personality among those who use DSM-V. The impact is likely to be less in the general public, which is likely to be aware only of the final diagnosis. Enlightened clinicians need work to educate the public on these issues.

Crosscutting assessments of areas relevant across disorders were also suggested for DSM-V, but do not represent the dimensional approach described above; rather dimensional assessments are included *in addition* to the traditional present-absent diagnoses in discrete categories. Although, as noted by the DSM-V workgroup, quantitative (i.e. dimensional) initial and follow-up assessments of symptom severity, distress, and impairment are extremely useful clinically, this process already has a long history in good quality clinical care. What is new is including these *non-diagnostic* assessments in the DSM. Furthermore, there are many decades of research on the reliability, validity, and clinical utility of many different instruments for such assessments, whereas the brief scales proposed for DSM-V will have minimal psychometric testing. Again, it is questionable whether clinicians paying increased attention to the diversity of severity within diagnoses (both across individuals and within individuals across time) will have a substantial impact on the public's stereotyping of the diagnoses themselves. As observed by Link and coworkers (1987, 1999), stigma is related much more to labels than to the details of clinical phenomena.

Risk syndromes

The APA is considering inclusion of a new category in which symptoms which place individuals at higher risk for developing a mental disorder at a later stage are identified. One set of proposed risk conditions are *psychosis risk syndrome* and *minor neurocognitive disorder*, suggested for people who present with milder versions of the symptoms found in psychotic disorders or dementia, respectively (APA, 2010c). The goal of these early diagnoses is to facilitate early detection of the warning signs of what may go on to develop into severe pathology, with the notion of facilitating early intervention, mitigation of long-term consequences, and reduction of damage to the brain as new treatments become available. The suggested categories hold clinical promise, but may have a negative, stigmatizing effect on those who are labeled with the new diagnoses. One concern, as stated by Dr. William Carpenter, chair of the psychotic disorders work group, is erroneously diagnosing those who are not truly at risk (APA, 2010c). Related to this point, is the fact that, inherent in the probabilistic definition of "risk", many people truly at risk do not go on to develop the disorder, presumably due to the presence of other, mitigating factors. The result of this classification may entail public and self-stigmatization in people who would not have received a pathological label otherwise, and may not even go on to develop the severe disorder they have already been "marked" for. It is unlikely that the negative stigma associated with psychosis or dementia will diminish as a result of the new classification. Rather, the stigma will likely expand to include more people, at an earlier age, and with less salient symptoms. We believe that in the same manner in which people identified as "at risk" for illnesses such as cardiac disease are monitored, encouraged to live healthy lifestyles, and treated without receiving pathologizing diagnoses prematurely, so should individuals at risk for mental disorders.

Autism spectrum disorders

The proposed new category will incorporate the current diagnoses of autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. The new category reflects recent advances in the field of autism and neurodevelopmental disorders showing that the symptoms of these disorders represent a continuum from mild to severe (APA, 2010d). This proposed change is being criticized by advocacy groups of the disorders considered "less severe" who currently view their condition as distinct. For example, the Asperger's Association of New England has written a letter to the DSM-V committee requesting that the Asperger's syndrome label remains unchanged as it clearly differentiates people with this disorder from other people on the autism spectrum, and has come to take an important role in the way many individuals understand themselves, and explain their experiences to their families and communities (AANE, 2010). Resistance to the new classification can be conceptualized as fear of *groupness* and perceived *homogeneity* – being viewed by the public as having much in common with the more severe, highly stigmatized label of autism. To help reduce public backlash, it may be necessary to change the name of the new diagnosis so that it is not anchored in the most severe of the disorders on the continuum. It may be prudent, more clinically representative, and less potentially stigmatizing to focus on the actual dimensions being assessed (i.e. social interaction and communication, presence of repetitive behaviors and fixated interests).

New proposed conditions

With every updated edition of the DSM, new, more specified, diagnoses are added. This is perceived as a reflection of advances in the scientific examination of mental illnesses and improvements in clinical assessment and symptom identification. For the upcoming DSM-V, there are a number of proposed diagnostic labels including *apathy syndrome*, *complicated grief disorder*, *parental alienation disorder*, *melancholia*, and more (APA, 2010e). We would like the reader to consider that along with the potential treatment gains that may be associated with these new diagnoses, there is also the risk of pathologizing what are essentially individual differences and diversity in human behavior. While some diagnostic labels offer relief, normalization, and a possible sense of shared destiny and community with others suffering from similar conditions, not all deviations from the norm in terms of affect, interpersonal functioning, and coping constitute a disorder. For example, different people will have different idiosyncratic patterns of coping with the loss of a loved one that will undoubtedly be influenced by their cultural background, social context, and nature of the relationship with the individual. Although these coping behaviors may be personally adaptive for the bereaved, they might be difficult for an outside observer to understand or assess. By introducing more and more diagnoses, we may narrow what is considered the range of "healthy functioning" to the point where few if any people meet such strict parameters.

Non-suicidal self-injury is an example of a proposed new DSM-V diagnosis that assigns a diagnostic label to a particular behavior (including its purpose). Although there is little doubt that this behavior is pathological, it is problematic to consider a behavior a disorder. Diagnostically labeling people based on a particular behavior will increase *groupness*, thereby suggesting the *homogeneity* of those who engage in non-suicidal self-injurious behavior and their distinction from both those with other disorders and the general public. It also will suggest that there is something stable that characterizes these individuals, as opposed to emphasizing a behavior that varies over time and may, in fact, completely

disappear. Through both increasing beliefs of *homogeneity* and *stability*, this new diagnosis is likely to increase both *public stigma* and *self-stigma*. In addition, in order to avoid this labeling, people engaging in non-suicidal self-injurious behavior may under report the frequency and severity of their actions, or avoid entering treatment altogether.

Summary

Diagnostic labels have clear clinical and research utility, but may have a number of negative implications for *public stigma*, *self-stigma*, and active *label avoidance* in people with mental illness. Through socio-cognitive processes of *groupness*, *homogeneity*, and *stability*, stigmatizing diagnostic labels may impact housing and job opportunities, as well as individuals' self-esteem, self-efficacy, and treatment utilization. Initial drafts of APA's DSM-V show a commendable trend of greater transparency and movement toward more dimensional approaches to diagnosis which may help reduce stigma in the future, but also include a number of proposals that may have a negative impact on stigma. Ultimately, clinicians using the DSM system need to be cognizant of potential stigma related pitfalls associated with generating summarizing diagnostic labels, and make continuous efforts to educate their patients and the public about these issues.

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