Abstract:

Introduction: The main objective of this paper is to offer an overview of the state of current knowledge about internalized stigma in people with severe mental illness.

Variables related to internalized stigma: This section highlights the primary socio-demographic, psychosocial and psychiatric variables related to internalized stigma.

Integrating models of internalized stigma: This section summarizes the most important integrating models proposed to explain the interplay of relationships in the field of internalized stigma.

Proposal of an empirical social-cognitive-behavioral model of internalized stigma: This section presents the results of a study conducted with a sample of 108 people with mental illness to propose a structural-equation model that encompasses social content (experiences of discrimination), as well as cognitive (stigma, internalized stigma and expectations of recovery) and behavioral (social functioning and personal autonomy) variables to explain the relationships between these variables in people with severe mental illness.

Implications for intervention: Overview of the effectiveness of psychological interventions in cases of internalized stigma and some guidance for future interventions and research.

Keywords: internalized stigma, schizophrenia, psychosocial rehabilitation, structural-equation models, discrimination.
to direct experiences of discrimination or social exclusion (Depla, de Graaf, van Weeghel and Heeren, 2005; Dickerson, Sommerville, Origoni, Ringel and Parente, 2002; Link et al., 1997; Link, Struening, Neese-Todd, Asmussen and Phelan, 2001; Markowitz, 1998, 2001; Wahl, 1999).

2. Variables related to internalized stigma

One crucial point of reference in research on internalized stigma in mental illness is the work of Livingston and Boyd (2010), who undertook the most thorough overview to date. They carry out a meta-analysis of the research into socio-demographic, psycho-social and psychiatric variables related to internalized stigma in mental illness. In their review of the scientific literature published until the year 2010, they found 127 articles related to the issue, of which only forty-five met their criteria for inclusion in the meta-analysis. The results provide very important information about the state of knowledge in this area. The most striking thing is how recent much of the research into internalized stigma is (97.8% of the works were published after 2000), how much of it has been carried out in the United States (44.4%) and Europe (33.3%), and the lack of research into intervention strategies; only two studies (4.4%) test out intervention programs geared toward internalized stigma (these studies are discussed in the last section of this work, which deals with intervention). In terms of variables with significant relations to self-stigma, the authors construct three categories:

Socio-demographic variables: None of the studied variables of this order (sex, age, education level, employment status, marital status, income level and ethnic group) has been demonstrated to have a significant relationship to internalized stigma in the group of persons with mental illness.

Psycho-social variables: The studies reviewed do find significant relationships between internalized stigma and variables like hope, self-esteem, empowerment, self-efficacy, quality of life, and social variables like social support and integration. In most studies, the coefficients are negative for all variables, with values ranging from -0.58 to -0.28. This group of studies reveals that there is a negative correlation between experienced stigma and quality of life and self-esteem (Depla et al., 2005; Link et al., 2001; Markowitz, 1998; Rosenfield, 1997). Experienced stigma reduces a sense of personal mastery and this, in turn, increases self-loathing on the part of the individual with mental illness (Wright et al., 2000).

Psychiatric variables: there is a positive correlation between the severity of symptoms (R=0.41) and internalized stigma, and a negative correlation between the severity of symptoms and adherence to treatment (R=-0.38). Startlingly, none of the other clinical variables studied – diagnosis, length of illness, hospitalizations, awareness of illness, functionality, or type of treatment – has been shown to have a significant relationship to self-stigma. In terms of symptomatology, the results are discordant. While some works report a positive correlation between self-stigma and symptoms of depression, psychosis and anxiety (Ertugrul and Ulug, 2004; Link et al., 1997; Markowitz, 1998), others indicate that there is no correlation with psychotic symptoms or overall symptomatology (Dickerson et al., 2002; Markowitz, 1998).

In terms of the methodology used, most of the studies are cross-sectional; only 13.3% of them include follow-up. Nonetheless, the results of those that do include follow-up are very significant as they evidence that internalized stigma is related to underuse of services, a greater number of unmet needs, greater emotional unease, a lower level of social adjustment, more severe depressive symptoms, and a lower level of adherence to medication.

Beyond the results of the aforementioned meta-analysis, the literature reveals some positive strategies used frequently by persons with mental illness to cope with stigma. Such strategies include looking for social support and getting involved in organizations and activities geared towards educating society about mental illness (Corrigan and Watson, 2005; Wahl, 1999). There are also maladaptive strategies, however, such as keeping illness a secret, withdrawing socially or seeking isolation as a way to avoid being rejected (Link et al., 1997; Muñoz, et al. 2009; Perlick et al., 2001; Vauth, 2007). The results would seem to demonstrate that individuals with larger and more effective social support networks are more likely to recover (Corrigan Gifford, Rashid, Leary and Okeke, 1999; Corrigan and Phelan, 2004; Liberman et al., 2002; Smith, 2000). Further, perception of stigma has been associated with a tendency towards social isolation and as an obstacle to recovery (Landeen, 2007). Empowerment seems to play an important role. Indeed, empowerment is one of the most widely studied variables in terms of the impact of internalized stigma on persons with mental illness (Corrigan and Garman, 1997; Rogers, Chamberlin, Ellison and Crean 1997). But the relationship between empowerment and self-stigma is not linear: the term “the paradox of self-stigma and mental illness” has been used to describe the observation that some individuals develop low self-esteem in the face of experiences of devaluation and discrimination, whereas others are relatively indifferent to the stigma or react to it with empowerment and anger (Corrigan, 2004; Deegan, 1990; Corrigan and Watson, 2002).

From a European perspective, one important study was carried out by GAMIAN-Europa (Global Alliance of Mental Illness Advocacy Networks, Broham, Elgie, Sartorius, Thronicroft and the GAMIAN Group, 2010), which investigated self-stigma, perceived discrimination, empowerment, and resistance to stigma in individuals with schizophrenia in fourteen European countries. The study was performed by means of a mail survey in those countries (which included Spain) (N=1229). Internalized stigma (ISMI, Ritsher and...
Phelan, 2004), empowerment (BUS, Rogers et al., 1997) and perceived discrimination (PDD, Link, 1987) were measured, and socio-demographic and clinical information collected. The results demonstrate that 41.7% of those interviewed experience self-stigma, 69.4% perceived discrimination, and 49.2% resistance to stigma at moderate or high levels. According to this study, the most predictive variables of internalized stigma were self-esteem/self-efficacy, empowerment, perceived discrimination, awareness of and agreement with diagnosis, and a large number of social contacts.

3. Integrating models of internalized stigma

A further step in the conception of internalized stigma entails the formulation of theoretical models that contemplate the interplay of variables that the research has revealed.

The group led by Patrick Corrigan is the one that has made the greatest contribution to research into stigma. Its many publications have formulated a model of the functioning of internalized stigma. The Social-Cognitive Model of Self-Stigma (Corrigan, Larson, and Kuwabara, 2008) maintains that, just like public stigma, internalized stigma consists of stereotypes, prejudices and discrimination. Individuals suffering from mental illness have prejudices against themselves and tend to agree with common stereotypes of mental illness. This prejudice, in turn, leads to negative emotional reactions, especially low self-esteem and self-efficacy (Wright et al., 2000). These self-prejudices can cause individuals with mental difficulties to quit their jobs and fail to lead independent lives (Link, Cullen, Struening, Shrivat, and Dohrenwend 1989).

Corrigan and Watson (2002; 2007) emphasize the importance of identifying with the stigmatized group. It is likely that those individuals who do not identify with the stigmatized group are indifferent to stigmatization as they do not feel that the prejudice and discrimination are addressed at them. Those who do identify with the group of persons with mental illness, on the other hand, apply the stigma to themselves (Jetten, Spears and Manstead, 1996). When they consider the stigmatizing attitudes legitimate, their self-esteem and self-efficacy are likely to be diminished (Link, 1987; Markowitz, 1998; Rüsch, Matthias, Angermeyer and Corrigan, 2005). If, on the other hand, they consider those attitudes illegitimate and unfair, they are likely to respond with anger (Frable, Wortman, and Joseph, 1997), which in many cases gives rise to greater empowerment. This also suggests that individuals reduce the size of their social networks and miss opportunities in anticipation of rejection due to stigmatization even before they have ever been hospitalized. This, in turn, leads to isolation, unemployment and, as a result, reduced income (Agerbo, Byrne, Eaton, and Mortensen, 2004; Mueller et al., 2006). The perception of stigma can also mean that individuals are less inclined to seek treatment (Wrigley et al., 2005).

Vauth (2007) formulated an empirical model of internalized stigma. That study aims to demonstrate how a diminished self-concept (self-efficacy and empowerment) mediates the psychological effects of self-stigmatization; he asserts that it plays a role in coping with stigmatization. The study involved 172 out-patients diagnosed with schizophrenia. Their levels of internalized stigma and perceived devaluation were measured, along with their ability to cope with stigmatization, their self-efficacy, empowerment, quality of life, and depression. Vauth’s primary hypothesis (2007) was that coping with stigmatization with strategies of social isolation and secrecy means an increase in levels of anticipatory anxiety. This, in turn, increases the levels of perceived discrimination and devaluation that then have negative effects on self-efficacy and empowerment. The decrease in empowerment has an effect on depression and eventually reduces quality of life. The results seem to support Vauth’s hypothesis, which was tested by means of a model of structural equations, as 46% of the reduction in depression and 58% of the improvement in the quality of life could be explained by empowerment. At the same time, 51% of the reduction in empowerment is due to a reduction in self-efficacy, higher levels of dysfunctional coping and of anticipated stigma. Together, these data suggest that an avoidance approach is a risk factor in stigma as it erodes self-efficacy and empowerment.

The third model is the one formulated by the Yanos, Roe and Lysaker group (Yanos, Roe, Markus and Lysaker, 2008; Lysaker, Roe and Yanos, 2007). Their model deepens the connections between internalized stigma, recovery and the results of interventions, studying internalized stigma, awareness of illness, symptomatology, self-esteem, hopelessness and coping in a sample of 102 individuals with schizophrenia. Their model is based on the hypothesis that internalized stigma increases avoidance behavior (avoidance coping and social avoidance) and depressive symptoms. These results are related to both hope and self-esteem. Thus, internalized stigma would have negative effects on employment insertion and symptomatology because it reduces hope and self-esteem, which in turn can trigger the beginning or worsening of depressive symptoms, social avoidance and an avoidance coping style. In this model, involvement in rehabilitation and expectations of recovery play an important role in the process of recovery of individuals with serious mental illness.

4. Empirical social-cognitive-behavioral model of internalized stigma

Though the articles reviewed have provided a major advance in knowledge of the variables at play in internalized stigma, they have not, in our view, fully established the role that each

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1 This model has been published by Muñoz, M., Sanz, M., Pérez-Santos, E. and Quiroga, M.A. (2010) in Psychiatry Research, 186, 402–408. It is discussed in considerable detail to help all readers, but especially Spanish-speaking readers, to understand it.
of these variables plays in the origin and the consequences of self-stigma in individuals with serious mental illness. In order to empirically identify the relationships between these variables, a study was designed that would consider the main social, cognitive and behavioral variables involved in internalized stigma. A social-cognitive-behavioral model of structural equations was formulated to facilitate understanding of the role that social stigma and experiences of discrimination play in the genesis of internalized stigma. The model would provide insight into how internalized stigma interacts with expectations of recovery to then influence the outcomes of psycho-social rehabilitation at a number of levels (Muñoz, Sanz, Pérez-Santos and Quiroga, 2011).

Procedure

The study was carried out at the Network of Social Services for individuals with serious and persistent mental illness in the Autonomous Community of Madrid. All the users of the network have been diagnosed with serious and persistent mental illness by the Office of Mental Health; they all receive psychiatric treatment and psycho-social rehabilitation. One hundred and eight individuals between the ages of eighteen and sixty-five with serious and persistent mental illness were interviewed. (For a detailed description of the methodology used, see Muñoz, Pérez-Santos, Crespo and Guillén, 2009 and Muñoz, Sanz, Pérez Santos and Quiroga, 2010).

Instruments

The following instruments were used:

- Socio-demographic variables: The questionnaire included questions on general socio-demographic information.

- Clinical variables: This information was taken from the clinical histories of participants; it included issues like diagnosis, symptomatology, and date of the beginning of the illness.

- Stigma: The definition in the Spanish translation of Attribution Questionnaire was employed (AQ-27) (Corrigan, Markowitz, Watson, Rowan and Kubik, 2003; Muñoz et al., 2009).

- Internalized stigma: The definition in the Spanish translation of Internalized Stigma of Mental Illness (ISMI) was employed (Muñoz et al., 2009) was employed. That scale assesses empowerment, coping skills and quality of life.

- Expectation of Recovery: The Spanish version of Recovery Assessment Scale (RAS) (Corrigan, Giffort, Rashid, Leary and Okeke, 1999; Muñoz et al., 2009) was employed. That scale assesses empowerment, coping skills and quality of life.

Experiences of direct discrimination: The evaluation of this variable was carried out through the assessment of subjectively perceived discrimination in eleven different situations in which individuals with mental illness might have felt discriminated against on the basis of their illness.

Analysis of the Data

A descriptive analysis of the socio-demographic and clinical variables was performed. Individuals were then assigned an internalized stigma score (ISMI, Ritsher et al., 2003). All the variables were analyzed in order to identify those with the greatest degree of variation; an analysis was then performed to establish a correlation between those variables and the overall ISMI score. Those variables that were found to be significant were selected for inclusion in the model of structural equations. The model was put into effect using the SPSS 16.0 and AMOS 7.0 programs. (SPSS, 2007; Arbuckle, 2006) (for a detailed description of the analysis and results, see Muñoz et al., 2011).

Results

In terms of socio-demographic characteristics (sex, age, educational level, etc.), the sample studied is similar to the overall population of people with mental illness who receive care at the Madrid network of social services (Rodríguez, Muñoz and Panadero, 2007), which supports its representativeness. Significantly, the importance of clinical variables is minor. This supports the findings of Markowitz (1998) and Vauth (2007) that there are no significant differences in the clinical characteristics found in the clinical history, such as diagnosis, duration of psychosis or the evolution of the disorder.

In function of the relationships found, we attempted to find a model of structural equations that would evidence the relationships between the different variables. After a number of trials, a highly explicative model (CMIN / DF = 1.429; p = .066; TLI = .944; CFI = .971; RMSEA = .063 (.000 to .105)) with suitable adjustment indexes ($\chi^2 = 40.0, \text{df} = 28$) was formulated.

INCLUDE FIGURE 1

Figure 1 shows that stigma and experiences of discrimination are two latent variables statistically dependent on the data of their associated subscales, based on the regression analysis. Analysis of the data found these to be significant (fear, avoidance, family/partner relationships, friends). The content of the latent-stigma construct is quantifiable in the
subscases of fear and avoidance, and avoidance is a great factor (0.60) than fear (0.53). The latent construct of experiences of discrimination is created by means of subscales of discrimination in the area of family and partner relationships (0.58), and discrimination in the area of friends (0.65).

Though not statistically significant, the covariance relationship between the variables of stigma and experiences of discrimination is necessary for the model to adequately fit the data. At the same time, stigma exercises an influence on the latent construct of the expectation of recovery in individuals with mental illness (with two split-half subscales with coefficients of 0.97 and 0.91), through a highly significant negative regression, and positively on internalized stigma. Expectations of recovery (split-half with 0.95 and 0.91) follow the opposite course: a positive relationship with internalized stigma and a negative relation with expectations of recovery. Finally, expectations of recovery and internalized stigma modulate behavioral results both in social functioning (0.83) and in personal autonomy (0.57).

Discussion

Given the above, this model combines social variables (experiences of discrimination), with cognitive (stigma, internalized stigma, expectations of recovery) and behavioral (psycho-social functioning, personal autonomy) variables that can be manifested in three discrete instances. Experiences of discrimination are considered clearly social in nature and stigma is considered cognitive-social. The first of these –experiences of discrimination– is directly related to experiences in the most immediate social environment (partner relationships/family and friends), and the second – stigma– depends mainly on fear and avoidance. According to some authors (Agerbo, Byrne, Eaton and Mortensen, 2004; Mueller et al., 2006), the social networks of individuals with mental illness tend to be small and to mediate the internalization of stigma. This might explain the great importance of partnership relationships/family and close friends in public stigma perceived by individuals with mental illness. At the same time, there is a positive relationship between public stigma and the number of experiences of discrimination. Likewise, the positive relationship found here between stigma and internalized stigma seems to be in keeping with previous studies (Jetten et al., 1996). It also furthers Hayward and Bright’s finding (1997) that many individuals with mental illness are familiar with the stereotypes about their group like, for instance, the belief that the mentally ill are incompetent, and hence individuals are likely to internalize those stereotypes. At the same time, the research seems to indicate that public stigma perceived by an individual can reduce self-esteem and self-efficacy, and limit the likelihood of recovery (Link, 2001; Rüsch et al., 2005; Wright, 2000). In this model, this hypothesis is evidenced by the influence that mostly social factors seem to exercise on mostly cognitive factors, like internalized stigma and expectations of recovery. Unlike Corrigan’s model (Corrigan and Watson, 2002; Corrigan, Watson and Barr, 2006), this model does not contemplate the differential factor that is identification or lack of identification with the stigmatized group, though that does not mean that it is not considered important in terms of cognitive-social processing. In keeping with Corrigan et al. (2008), here public stigma seems to have a negative relationship to expectations of recovery and a positive relationship to internalized stigma, whereas experiences of discrimination seem to invert this tendency, with a positive relationship to internalized stigma and a negative relationship to expectations of recovery.

Figure 1. Proposed Structural Equation Model.

Note. The structural equation model: the rectangles represent observed variables. The ovals represent unobserved latent variables. The number next to each connector is the value of the standardized regression weights, and their significance is represented with asterisks: * p < .05, ** p < .01, *** p < .001.
In the third instance, in keeping with Link’s observations (1987) it is likely that the internalization of public stigma yield diminished cognitive and behavioral functioning on the part of the person with mental illness. It is also known that stigma can become a hindrance to access to health care, treatment, social resources, social inclusion and opportunities for recovery (Kadri and Sartorius, 2005; Wahl, 1999; Wrigley, Jackson, Judd and Komiti, 2005). Previous studies that have employed the same instrument to measure expectations of recovery (RAS, Corrigan et al., 1999) suggest that the overall result of the scale is associated with psycho-social functioning and symptomatology (Corrigan et al., 1999). Similarly, some studies indicate that stigma exercises a negative influence on the breadth and quality of social networks and, hence, social functioning (Angell, Cooke and Kovac, 2005; Link et al., 1989; Yanos, Rosenfield and Horwitz, 2001). Along these lines, it is known that widespread perception of stigma can affect a person’s social functioning (Lysaker, Roe and Yanos, 2006). In the model formulated in this study, this set of data is tackled at the third stage, which means that the aforementioned processes influence the observable results in psycho-social functioning in terms of two questions: social functioning and personal autonomy. Both questions bear an inverse relationship with internalized stigma and a direct relationship with expectations of recovery. Vauth (2007) indicates how the relationship between internalized stigma and the results in psycho-social functioning and depressive symptomatology are mediated by self-efficacy and empowerment. Although repeated attempts were made to include empowerment in this model, it was not possible to isolate it from internalized stigma, and hence it was excluded. Similarly, we have not included explicit measures of self-efficacy. It has been stated above that in the sample studied symptomatology (mainly psychotic, and not exclusively depressive, in nature) seems to be unrelated to internalized stigma. We believe that a model where the relationship between internalized stigma and behavioral results is more explicit might include the variables formulated by Vauth (2007) – coping, self-efficacy and empowerment – and the ones identified by Corrigan and Watson (2002; 2006) that address the different ways of internalizing public stigma insofar as there is greater or lesser identification with the stigmatized group.

5. IMPLICATIONS FOR INTERVENTION

In reviewing the literature on efficacious interventions to alleviate or remedy the effects of internalized stigma, one encounters a large number of recommendations based on the underlying theoretical models and research involving different variables and factors deemed relevant. Empowerment of individuals with mental illness and/or their families seems to play a key role in the struggle against the internalization of stigma (Corrigan et al., 2008). Further, a positive correlation has been observed between resistance to stigma (Sibitz, Unger, Woppmann, Zidek and Amering, 2011), self-esteem, empowerment and quality of life, and a negative correlation between stigma and depression. Similarly, an adequate social network, being married or single (not separated) and receiving out-patient treatment bear a positive relationship to resistance to stigma. Likewise, and in keeping with this model, Tsang, Fung and Chung (2010) have found that in individuals with schizophrenia, the relationship between self-stigma (low levels), state of change (preparedness for taking action), and overall functioning (good functioning) are predictors of adherence to intervention. That is, intervention on internalized stigma should be geared towards helping individuals to further states of change until they are prepared to take action and to stick with proper psychiatric and psycho-social treatments. It appears that psycho-social rehabilitation should focus on the recovery and/or improvement of the individual’s social network and on empowering the individual with mental illness and his or her family to improve self-esteem, self-efficacy and quality of life.

Nonetheless, there is little empirical data on the efficacy of the interventions proposed. Indeed, in the aforementioned review of the literature Livingston and Boyd (2010) found only twenty-two studies that included longitudinal measures of self-stigma, of which only six met the criteria for inclusion. More significantly still, only two of those studies discuss changes that occur over time due to intervention. Griffiths, Christensen, Jorn, Evans and Groves (2004) found that interventions yielded moderate but significant effects on individuals with depression. MacInnes and Lewis (2008), on the other hand, found that brief (six-week) cognitive group intervention was somewhat effective in individuals with serious and persistent mental illness who were also using psycho-social rehabilitation services. Such intervention was able to effect a significant reduction in internalized-stigma variables, but there was no correlation between that change and levels of self-esteem, self-acceptance and/or overall psychological wellbeing.

Recently, Roe, Hasson-Ohayon, Derhi, Yanos and Lysaker (2010) have compared the efficacy of narrative techniques and cognitive therapy for improvement of internalized stigma with positive results. A number of different positive effects are yielded, such as: qualitative improvements in experiential learning, positive changes in the experience of the self, the acquisition of new cognitive skills, greater levels of hope, improved coping and emotional changes. These results seem to be reinforced by factors such as therapeutic alliance and the active role played by participants in the intervention.

Most certainly, the state of research on internalized stigma and, more specifically, the model formulated here help to create a framework for reflection and research into the emergence, continuance and effects of internalized stigma.
They also offer certain keys in the struggle against stigma, which should be geared towards structural and social actions that reduce public stigma and the social barriers that it means for the groups involved. This can mean the recognition and defense of rights (in, for instance, the United Nations Convention on the Rights of Persons with Disabilities or The Green Book on Mental Health in Europe), as well as individual legal and judicial actions, ongoing and mass-scale awareness and defense campaigns in schools and the media (for example, the Changing Minds campaign in England). The struggle against stigma can also mean working with families and individuals close to persons with serious mental illness (friends, educators, employers, and so forth.) to help lessen the impact of discrimination against individuals with mental illness in their most immediate and frequent social environments. In closing, we would like to emphasize the need to strengthen areas of research that enable professionals who work directly with users of mental health services to implement programs and lines of intervention geared towards enabling the person with mental illness to increase personal autonomy, lead an independent life, make the most of his or her skills, and shift identification with and personal and social action in relation to stigma in order to facilitate social integration.

REFERENCES


**Acknowledgements**

This work was co-funded by the Cajamadrid Social Foundation and the Autonomous Community of Madrid. The authors would like to thank María Crespo, Ana Isabel Guillén and María de los Ángeles Quiroga for their help during different phases of the initial study.