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Self-stigma, perceived discrimination and empowerment among people with a mental illness in six countries: Pan European stigma study



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ABSTRACT

A cross-sectional study including 796 individuals with a psychiatric disorder was conducted in Croatia, Israel, Lithuania, Malta, Romania and Sweden in 2010 aiming to assess correlates of self-stigma. The Internalized Stigma of Mental Illness (ISMI) was used to measure self-stigma, whereas the Boston University Empowerment Scale was used to measure the self-efficacy/self-esteem (SESE) and sense of power/powerlessness (PP). Perceived discrimination and devaluation was measured with the Perceived Devaluation and Discrimination (PDD) Scale. Thirty three percent of participants had moderate-to-high ISMI scores. In multivariable-adjusted analysis, significant 'predictors' of high ISMI scores were: age-group of 50–59 years, current employment, lower social contacts, and minimal-to-low SESE and PP scores. Remarkably, no significant association between ISMI and PDD was evident. Furthermore, there was evidence of a significant interaction between SESE and country. Study participants might not be representative to all individuals with mental disorders in countries included in this survey. Our findings indicate that people with psychiatric diseases suffer both self-stigma and perceived discrimination and devaluation. This is one of the very few reports highlighting country differences and diagnosis disparities of self-stigma among individuals with mental illnesses. Between-country differences should be considered and carefully addressed in the process of policy formulation and interventional programs against stigma.

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1. Introduction

Stigma contributes to the hidden burden of various illnesses. With regard to psychiatric disorders, stigma can be both an attribute and cause of the disease and, therefore, it may become a 'second disease' involving a critical downward spiral. It is estimated that between 27% (World Health Organization, 2012) and 38% (Wittchen et al., 2011) of the European Union (EU) population is affected by a mental disorder every year.

Overall, stigma can be defined as the 'social-status loss and discrimination triggered by negative stereotypes that have become linked in a particular society' (Ritsher and Phelan, 2004). Thus, stigma is a socially constructed concept, which addresses three interacting levels: *institutional* (structural stigma), *interpersonal* (social stigma) and *individual* (self-stigma) (Livingston and Boyd, 2010). Structural stigma occurs at a macro-level and can appear in rules, policies and practices of both public and private entities, since inherent authority enables them to control and limit the rights and chances of persons of minority groups (Corrigan et al.,

2004). Conversely, interpersonal stigma occurs at a meso-level. Public or social stigma is the phenomenon of both endorsement and discrimination of the general population or social groups against stigmatized persons (Corrigan et al., 2005; Corrigan and Watson, 2002).

Although obvious discrimination and social exclusion is often reported by people with a mental illness, it is important to consider that the harm caused by stigma is not merely a direct result of the discrimination by others (Lauber, 2008). Rather, stigma operates through the internalization of the public attitudes and beliefs by the stigmatized person.

Thus, internalized stigma, that is self-stigma, can be generally described as the subjective and internal experience of stigma. A concise definition is provided by Ritsher et al. (2003): 'Internalized stigma is the devaluation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself.'

A series of studies have shown that people with a psychiatric disorder who endorse negative stereotypes suffer from a variety of deleterious consequences such as unemployment, income loss, lower self-esteem, self-efficacy, empowerment and less treatment-seeking behavior (Brohan et al., 2010a, 2010b, 2011; Sharac et al., 2010; Vauth et al., 2007; Vogel et al., 2007; Wright et al., 2000). In contrast, mentally ill persons, who are aware of the negative labels but do not

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apply those to themselves, suffer much less or even remain unaffected (Rüsch et al., 2006).

Accordingly, there is generally consent that stigma is not inherent, but rather it develops in a socio-cultural context. From this point of view, the relationship- and context-interconnection of stigma is fundamental of the appreciation and research of the concept (Corrigan and Watson, 2002; Major and O'Brien, 2005). Therefore, it is essential to reduce internalized stigma and its negative effects on various outcomes exploring the underlying processes of internalized stigma, especially considering country and culture differences.

Corrigan et al. (2009) emphasize that self-stigma is not only 'there' (or, 'not there'), but it is a multilevel process with three sequential stages namely the 'three A's: stereotype awareness, agreement and application to oneself. Hence, the first step is the awareness of the social stigma. Specifically, this means the picture of the general public and their imaginable behavior towards the stigmatized group to which the person belongs, for instance mentally ill people in general, or someone with depression in particular (Corrigan et al., 2009, 2006). Subsequently, the individual either endorses the stereotype, or dissents it. The internalization of the stigma and application to people with psychiatric disorders or depression is referred to as 'stereotype agreement'. Nonetheless, self-stigma only develops if the third stage is also passed through the application of the stereotype to oneself, which can be denoted as 'self-concurrence' (Corrigan et al., 2009). Widespread stereotypes about people with psychiatric disorders include blame, dangerousness, and incompetence (Corrigan et al., 2009).

To date, numerous studies have measured consequences of self-stigma, but such studies have been mostly restricted to one country only and have focused on a specific mental disorder (Livingston and Boyd, 2010). On the face of it, there is an obvious gap in stigma research.

This study aims to explore cultural and national disparities in self-stigma and its association with several key characteristics, which are putative predictors of the occurrence of internalized stigma. These factors include socio-demographic and socioeconomic characteristics, psychiatric disorders, and psychological factors [self-esteem and self-efficacy, which are regarded as mediators of self-stigma (Corrigan et al., 2009)].

Since previous studies have focused on specific countries, the exploration of socio-cultural disparities is central in this paper. Therefore, to the best of our knowledge, this is one of the very few reports aiming to identify country differences of the underlying processes of self-stigma. We hypothesized between-country differences in the levels of self-stigma due to specific socioeconomic and cultural differences in six countries under investigation. This is based on the social dominance theory (SDT). The SDT provides a framework for integrating causes and effects of prejudice and discrimination both on the individual and on the societal level. Fischer et al. (2012) conducted a meta-analysis, focusing on macrocontextual factors, inferring that 'social dominance orientation (SDO) can be viewed as a general preference for group-based hierarchy that predicts prejudice'. The authors concluded that the aggregate level of social dominance varied considerably between the 27 tested countries. Higher SDO means were significantly related to less democracy, gender empowerment, lower gross national income and lower level of egalitarianism. Hence, group hierarchies are context-specific and shaped by the socialization into a social system (Fischer et al., 2012).

2. Methods

2.1. GAMIAN-Europe

A cross-sectional study was conducted by 'Global Alliance of Mental Illness Advocacy Networks-Europe' (GAMIAN-Europe, a non-for-profit organization) in six countries in 2010.

2.2. Study population

The survey included 796 participants with a psychiatric disorder who were all members of an associative GAMIAN-Europe organization in one of the following six countries: Croatia, Israel, Lithuania, Malta, Romania, and Sweden. In all countries, inclusion criteria were the same and consisted of the following: age of individuals (≥ 18 years); physician-verifiable diagnosis of psychiatric disorder based on standardized procedures/protocols; informed consent expressing individuals' willingness to participate in the study.

All partner organizations of GAMIAN-Europe received an e-mail with detailed explanations about the study aim and the request to inform their individual members about the survey. Most organizations put a link on their website, which directs users to the online questionnaire. Further means of recruitment of participants comprised notifications in monthly magazines of the partner organizations, information during meetings and different events, and distribution of questionnaires which were subsequently returned to GAMIAN organization by means of regular mail.

In each country, the survey was approved by the respective Institutional Review Boards.

2.3. Instruments

2.3.1. The Internalized Stigma of Mental Illness Scale (ISMI)

Self-stigma, or internalized stigma, was measured with the 'Internalized Stigma of Mental Illness Scale'. The instrument is categorized in the following five subscales: alienation, stereotype endorsement, discrimination experience, social withdrawal, and stigma resistance. Respondents rate on a four-point Likert scale whether they strongly disagree (1), disagree (2), agree (3), or strongly agree (4) with the given first person statements. In the analysis, the ISMI stigma resistance subscale was reverse-scored, so as higher scores imply higher self-stigma in line with previous reports on this matter (Ritsher et al., 2003). The ISMI has shown a good internal consistency (Cronbach's $\alpha=0.90$) and a good stability over time (test-retest reliability coefficient: $r=0.92$) (Ritsher et al., 2003).

In the analysis, ISMI was treated as a continuous variable, but also it was dichotomized into: minimal-low (average score ≤ 2.5) vs. moderate-high (average score > 2.5) (Brohan et al., 2010a, 2010b, 2011).

2.3.2. The Perceived Devaluation and Discrimination Scale (PDD)

Link developed the 'Perceived Devaluation-Discrimination Measure' with 12 items and a six-point scale which ranges from 'strongly agree' to 'strongly disagree'. The PDD measures felt stigma, which is the estimation how the society appraises people with a psychiatric disorder and mental health service users (Link, 1987, S. 102) (Link et al., 2001). The scale of half of the questions is reversed. The reliability of this measure has been reported to vary between $\alpha=0.78$ and $\alpha=0.88$.

In the analysis, PDD was dichotomized into: minimal-low (average score ≤ 2.5) vs. moderate-high (average score > 2.5), based on prior reports from GAMIAN study as described by Brohan et al. (2010a, 2010b, 2011).

2.3.3. The Boston University Empowerment Scale (BUES)

The 'Boston University Empowerment Scale' was developed in 1997 for consumers of mental health services. In its original it contains 28 items which reveal five underlying dimensions of empowerment: self-efficacy/self-esteem, power/powerlessness, community activism, righteous anger, and optimism/control over the future (Rogers et al., 1997). In this survey, only two subscales were used, self-efficacy/self-esteem (SESE), and power/powerlessness (PP). The 17-item scale has already shown a good internal consistency reliability coefficient between $\alpha=0.85$ and 0.86 (Ritsher et al., 2003; Brohan et al., 2011). This entails another benefit which Corrigan et al. observed. All subscales of the BUES load either on one of two factors. The authors define them as 'self-orientation' which includes self-efficacy, and self-esteem inter alia, and 'community orientation' which covers power/powerlessness amongst others (Corrigan et al., 1999).

In the analysis, SESE and PP were both dichotomized into: minimal-low (average score ≤ 2.5) vs. moderate-high (average score > 2.5) (Brohan et al., 2010a, 2010b, 2011).

2.3.4. Socio-demographic and socioeconomic characteristics, clinical parameters and social contact items

Socio-demographic and socioeconomic data, illness-related and social contact information were also include in the questionnaire. More specifically, demographic and socioeconomic variables included sex, age (18–30, 31–49, 50–59, and ≥ 60 years), educational level (primary, secondary, and university degree), and employment status (in the analysis, dichotomized into: employed vs. unemployed and/or retires). Clinical questions combined self-reported diagnosis (bipolar syndrome, depression, psychosis, and other diagnosis), age at first diagnosis, agreement with diagnosis (dichotomized into: yes vs. no), present treatment status and current main type of mental healthcare. Social contact variables contained questions regarding the living situation, relationship status, level of contact with the family,

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