Journal of Affective Disorders 129 (2011) 56–63

Contents lists available at ScienceDirect

Journal of Affective Disorders

journal homepage: www.elsevier.com/locate/jad

Research report

Self-stigma, empowerment and perceived discrimination among people with bipolar disorder or depression in 13 European countries: The GAMIAN–Europe study

Elaine Brohan [a,*], Dolores Gauci [b], Norman Sartorius [c], Graham Thornicroft [a] and For the GAMIAN–Europe Study Group [1]

[a] Health Service and Population Research Department, Institute of Psychiatry, King's College London, England
[b] GAMIAN–Europe, c/o FAIB Federation of European and International Associations, 40, rue Washington, 1050 Brussels, Belgium
[c] Association for the Improvement of Mental Health Programmes, 14 Chemin Colladon, 1209 Geneva, Switzerland

ARTICLE INFO

Article history:
Received 5 August 2010
Received in revised form 3 September 2010
Accepted 3 September 2010

Keywords:
Self-stigma
Bipolar disorder
Depression
Empowerment
Perceived discrimination
Europe

ABSTRACT

Background: There is little information on the degree to which self-stigma is experienced by individuals with a diagnosis of bipolar disorder or depression across Europe. This study describes the levels of self-stigma, stigma resistance, empowerment and perceived discrimination reported in these groups.
Methods: Data were collected from 1182 people with bipolar disorder or depression using a mail survey with members of national mental health non-governmental organisations.
Results: Over one fifth of the participants (21.7%) reported moderate or high levels of self-stigma, 59.7% moderate or high stigma resistance, 63% moderate or high empowerment, and 71.6% moderate or high perceived discrimination. In a reduced multivariate model 27% of the variance in self-stigma scores, among people with a diagnosis of bipolar disorder or depression, was accounted for by levels of empowerment, perceived discrimination, number of areas of social contact, education and employment.
Limitations: Findings are limited by the use of an unweighted sample of members of mental health charity organisations which may be unrepresentative of the reference population.
Conclusions: These findings suggest that self-stigma occurs among approximately 1 in 5 people with bipolar disorder or depression in Europe. The tailoring of interventions to counteract (or fight against) the elements of self-stigma which are most problematic for the group, be they alienation, stereotype endorsement, social withdrawal or discrimination experience, may confer benefit to people with such disorders.

1. Introduction

Self-stigma is a personal response to perceived mental illness stigma (Corrigan and Watson, 2002). It can be considered a transformative process wherein a person loses his or her previously held or desired identities, e.g. as a parent, employee, friend, partner etc to adopt a stigmatised and devalued view of themselves (Yanos et al., 2008).

A recent review of 57 studies using a quantitative measure of mental illness stigma found a predominant focus on a general illness category such as psychiatric disorders or severe mental illness (SMI) or else on schizophrenia or other psychotic disorders (Brohan et al., 2010). The majority of studies (52.6%) used a sample with SMI, 28.1% considered schizophrenia or psychotic disorders alone, 3.5% considered bipolar disorder alone, 8.8% considered depression alone and 7% considered

* Corresponding author. Tel.: +44 207 848 0570; fax: +44 207 848 1462.
E-mail address: elaine.brohan@iop.kcl.ac.uk (E. Brohan).
[1] Members listed at end of the paper.

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doi:10.1016/j.jad.2010.09.001

other diagnoses. This highlights a pattern of considering bipolar disorder and depression in combination with psychotic disorders as part of the general category of SMI, or considering schizophrenia or other psychotic disorders alone, with little research focusing on these conditions specifically. This study considered three elements of stigma: 1) perceived stigma, 2) experienced stigma and 3) self-stigma. Perceived stigma is the belief that the public hold negative attitudes towards people with a mental health problem and the fear or expectation that others will behave in a discriminating way towards them while experienced stigma refers to instances of unfair treatment or discrimination due to having a mental health problem. Of the identified studies, 79% used a measures of perceived stigma, 46% a measure of experienced stigma and 33% a measure of self-stigma. This suggests that as well as an under-representation of bipolar disorder and depression in stigma research, there is also a limited focus on measuring self-stigma.

However, there is a growing interest in further examining the stigma related to bipolar disorder and depression, with several recent studies focusing on the development of specific measures for use with individuals with a diagnosis of depression (Gabriel and Violato, 2010; Kanter et al., 2008). There has also been an emergence of qualitative work considering experiences of stigma in people with bipolar disorder and depression (Barney et al., 2009; Lim et al., 2004; Michalak et al., 2006).

In studies of patients with a diagnosis of bipolar disorder or depression, self-stigma has been associated with reduced quality of life (Yen et al., 2005), lower self-esteem (Ritsher and Phelan, 2004; Werner et al., 2009), reduction of morale (Ritsher and Phelan, 2004) and increased avoidance behaviours (Kanter et al., 2008; Manos et al., 2009). It is also associated with greater depression severity (Kanter et al., 2008; Manos et al., 2009; Raguram et al., 1996; Ritsher and Phelan, 2004; Rusch et al., 2008; Yen et al., 2005), having been in treatment for depression (Kanter et al., 2008; Rusch et al., 2008), more negative attitudes towards treatment seeking (Conner et al., 2010) and lower treatment compliance in those with a diagnosis of depression (Fung et al., 2007).

Perceived stigma is associated with decreased quality of life (Alonso et al., 2009), lower self-esteem (Hayward et al., 2002), decreased work and role functioning (Alonso et al., 2009) and increased restrictions in the frequency or quality of social and leisure activities (Perlick et al., 2001; Alonso, et al., 2009). It is also associated with greater depression severity (Pyne et al., 2004; Sirey et al., 2001), increased number of unmet mental healthcare needs (Roeloffs et al., 2003) and reduced medication adherence (Sirey et al., 2001).

The burden that stigma adds to that produced by mental illness is not well recognised. Self-stigma can be considered a marker of burden of illness, a barrier to recovery and an area for intervention, however there is currently a lack of evidence on the degree to which self-stigma is experienced by individuals with a diagnosis of bipolar disorder or depression across Europe. This study also considered levels of perceived discrimination, empowerment and stigma resistance across Europe. These additional variables were selected as existing evidence suggests that these variables may be particularly useful to consider in building a picture of self-stigma as evidenced by the reviewed literature.

This study builds on earlier work which considered levels of self-stigma among those with a diagnosis of schizophrenia or other psychotic disorder across 14 European countries ($n=1229$) (Brohan et al., in press). The results of that study suggested that self-stigma appears to be common and sometimes severe among people with schizophrenia or other psychotic disorders in Europe with almost half (41.7%) reported moderate or high levels of self-stigma. The current study analyses data collected at the same time and using the same methods as this previous study. As discussed, although there is a growing interest in examining the stigma experiences of individuals with a diagnosis of bipolar disorder or depression, to date research in this group has been limited particularly within the European context. For this reason, this second study focuses individuals with a diagnosis of bipolar disorder or depression.

It aims to (1) describe the level of self-stigma experienced by people with a diagnosis of bipolar disorder or depression in Europe; (2) examine the degree to which stigma resistance, perceived discrimination and empowerment as well as socio-demographic, illness-related and social contact variables are associated with self-stigma in this sample; and (3) draw implications for mental health services in European countries.

2. Methods

2.1. Study design

The study had a cross-sectional design where participants completed a mail survey measuring levels of self-stigma, stigma resistance, empowerment and perceived discrimination at one point in time. Surveys were sent through member organisations of the Global Alliance of Mental Illness Advocacy Networks (GAMIAN–Europe). GAMIAN–Europe is a patient lead organisation which represents the interests of persons affected by mental illness (GAMIAN–Europe, 2007). Its main objectives include: advocacy, information and education and fighting stigma of mental illness and consequent discrimination. It includes 74 full member organisations in 32 countries.

2.2. Participants

Data were collected in twenty European countries (see acknowledgments for all participating organisations). The following countries were involved: Belgium, Bulgaria, Croatia, the Czech Republic, Estonia, Finland, France, Greece, Italy, Lithuania, Macedonia, Malta, Poland, Romania, Russia, Slovenia, Spain, Sweden, Turkey and the Ukraine (2 sites). This paper focuses only on data collected from participants with a self-reported diagnosis of depressive disorders and bipolar illness. The study was not restricted to participants with these diagnoses and data from those with other diagnoses will be reported elsewhere. An arbitrary cut-off of 30 cases was used for including sites in descriptive and inferential analyses. This excluded data from Russia ($n=16$), Slovenia ($n=23$), the Czech Republic ($n=26$), France ($n=11$), Turkey ($n=7$), Bulgaria ($n=22$) and the Ukraine site a ($n=23$) and the Ukraine site b ($n=4$). The remaining 13 sites were included.

2.3. Procedure

The study survey was sent to a random sample of 500 people at each study site with the aim of recruiting a