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Research report

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

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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.

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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

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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 measure 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

minimum of 200 people into the study. The selection of participants was conducted by staff at each study site and was overseen by GAMIAN–Europe. The sample was selected by considering the total membership of the organisation and sending a survey pack to those who appeared at an appropriate number on the membership list (e.g. every third or every tenth). At several sites with a smaller membership, survey packs were also distributed to patients at services run by the organisation, e.g. day centres.

The estimate of recruiting 200 people by sending 500 survey packs was based on a response rate (50%) achieved in a similar survey study conducted by GAMIAN–Europe (Morselli and Elgie, 2003). Each potential participant was mailed a survey pack containing scales which measured self-stigma, stigma resistance, empowerment, perceived discrimination and socio-demographic details. Each pack contained a stamped addressed envelope for the participant to return the survey to the study site. Each pack also contained an information sheet and contact details of the site coordinator should the participant wish to ask any questions. The coordinator was available to assist the participant with aspects of completing the survey and on occasion, at the participant's request, the survey was completed as a face to face or telephone interview.

2.4. Measures

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

The ISMI is a 29-item scale that assesses self-stigma. It is composed of 5 subscales: Alienation, Stereotype Endorsement, Perceived Discrimination, Social Withdrawal and Stigma Resistance. Strong internal consistency ($\alpha=0.90$) and test–retest reliability ($r=0.92$) have been reported for the ISMI (Ritsher and Phelan, 2004).

Recent research has suggested that the 'Stigma Resistance' subscale is conceptually different to the other subscales (Lysaker et al., 2008; Sibitz et al., 2009). For this reason, stigma resistance (SR) is considered as a separate construct to self-stigma throughout this paper. Self-stigma refers to the summed average of the other 4 ISMI subscales.

2.4.1.1. *The Boston University Empowerment Scale (BUES)*. Empowerment was measured using the BUES (Rogers et al., 1997). A 17-item version consisting of the self-esteem/self-efficacy (SESE) and power/powerlessness (PP) subscales of the original scale was used in a recent study (Ritsher et al., 2003). Although not formally validated, this version demonstrated adequate internal consistency ($\alpha=0.86$) in the above mentioned study, which suggests that it is appropriate to use as a stand alone measure.

2.4.1.2. *The Perceived Devaluation and Discrimination Scale (PDD)*. The PDD is a 12-item unidimensional scale which measures the extent to which a person believes that most people will devalue or discriminate against someone with a mental illness (Link, 1987). A high level of perceived devaluation and discrimination is indicated by agreement with six of the items and by disagreement with six others. This scale has been widely used and has excellent psychometric properties (Link et al., 1991).

2.4.1.3. *Socio-demographic, illness-related and social contact questions*. Participants completed a number of self-report questions on socio-demographic, clinical and social contact variables. Socio-demographic variables included gender, age, education, housing situation, employment and source of income. Clinical variables included self-reported diagnosis; age at first diagnosis; level of agreement with diagnosis; current treatment status and current main type of mental healthcare. Social contact variables included living situation; relationship status; level of contact with family; presence of a friend and presence of a confidant or 'best' friend.

2.5. Ethical considerations

Full ethical approval was obtained from the King's College London Research Ethics Committee (Ref: CREC/06/07-18). Approval of local ethics committees was obtained in all participating countries.

2.6. Translation procedure

In non-English speaking countries, a consistent translation and cross-cultural adaptation procedure was adopted to ensure that the survey packs were as comparable as possible. All survey materials were translated from English into the target language, ensuring that the translator had the target language as his/her first language, and had English as his/her second language. The translator was provided with background information on the purpose of the study to ensure that a contextual understanding of items was achieved. The site coordinator then reviewed the translated survey materials and discussed any problematic translations within the study team to resolve disputed items. This is in keeping with established methods for translation (Sartorius and Kuyken, 1994).

2.7. Data analysis

All analyses were performed using SPSS version 15 and Stata version 9.2.

Descriptive statistics for the socio-demographic, illness-related and social contact variables were calculated. An overall score for the number of areas of social contact was calculated by recoding the 5 socio-demographic items so that 0 = no social contact and 1 = social contact. A count score was then provided for the number of areas in which social contact was reported (possible range 0–5). Employment was recoded into a binary variable with one category representing working full-time, part-time, volunteering or student and the other category representing unemployed or retired. Highest level of education recoded into a binary variable with one category representing university or college education and the other category representing non university education (including primary school, secondary school, apprenticeship training etc).

All four study measures (ISMI, SR, PDD, and BUES) are scored on a 4-point Likert scale with possible scores ranging from 1–4, so that a higher total score indicates a higher level of the attribute. Previous studies have represented a high level of self-stigma as an average score above the midpoint of 2.5 (Ritsher and Phelan, 2004; Ritsher et al., 2003). In this

study 4 categories were used: <2 minimal stigma, 2–2.5 low stigma, 2.5–3 moderate stigma and 3+ high stigma (Lysaker et al., 2008). Descriptive statistics were calculated for all scale and subscale scores. The overall internal consistency for each of the four measures and degree of correlation between the four total scores were also calculated.

Analysis of variance (Anova) was applied to the four total scores to examine between-country differences. *T*-test or Anova was also used to examine differences between groups on the basis of gender, education, employment, agreement with diagnosis and current treatment. The relationship between self-stigma (the dependent variable) and the independent variables of empowerment (SESE), empowerment (PP), stigma resistance, perceived discrimination, number of areas of social contact, gender, employment status, level of agreement with diagnosis, level of education and diagnosis were further explored using clustered univariate and multivariate regression. The amount of variance in self-stigma associated with each independent variable was assessed using clustered univariate analysis. The variables which demonstrated significant associated were then considered in the reduced multivariate analysis.

3. Results

3.1. The sample

1314 survey packs were returned from 20 sites. 1182 surveys from 13 sites were included for analysis, excluding 132 surveys from 7 sites where <30 surveys were returned by participants with a diagnosis of bipolar disorder or depression. For the 13 included sites, the overall response rate was 65%. Response rates within country ranged from 29% in Belgium to 93% in Macedonia and Croatia. There was a midpoint response rate of 71% in Spain. Participants in this sample had a self-reported diagnosis of depression (51.1%) or bipolar disorder (48.9%). 66% were female and 39.9% of participants were

engaged in some form of work or study. Mean number of areas of social contact was 3.2 (SD = 1.04). Additional socio-demographic and illness-related information is displayed in Table 1.

3.2. Scoring and scale structure

The internal consistency for the 24-item ISMI was $\alpha = 0.94$. The SR subscale had an internal consistency of $\alpha = 0.59$. The other 4 subscales had the following values: alienation ($\alpha = 0.83$), stereotype endorsement ($\alpha = 0.81$), discrimination experience ($\alpha = 0.83$) and social withdrawal ($\alpha = 0.85$). The PDD had an internal consistency of $\alpha = 0.86$. The 17-item BUES had an internal consistency of $\alpha = 0.86$. The SESE subscale had an internal consistency $\alpha = 0.92$ and the PP subscale had an internal consistency $\alpha = 0.71$.

Table 2 presents the results of grouping ISMI, SR, PDD, BUES and subscales scores using the minimal, low, moderate and high categories. This places 21.7% of self-stigma scores in the moderate or high category. 59.7% of stigma resistance scores, 63% of empowerment scores and 71.6% of perceived discrimination scores were in the moderate to high category.

There were strong and highly significant correlations between self-stigma and the other measures: ISMI and BUES ($r = -0.67, p = 0.001$), ISMI and SR ($r = -0.24, p = 0.001$), ISMI and PDD ($r = 0.36, p = 0.001$). Number of areas of social contact ($r = -0.16, p = 0.001$) and age at first contact with mental health services ($r = -0.06, p = 0.05$) were significantly associated with self-stigma.

Participants who were employed had significantly lower self-stigma scores ($t = 6.00, p = 0.001$). Those with a diagnosis of depression had significantly higher scores than those with a diagnosis of bipolar disorder ($t = 1.56, p = 0.001$). Those who had college or university education had significantly lower scores than those who had primary level (mean difference = $-0.33, p < 0.001$) or secondary level education (mean difference = $-0.30, p < 0.001$) (one-way Anova $F(3,$

Table 1
Socio demographic, illness-related and social contact characteristics of participants.

Variable		N ^a	%
Gender	Male	399	33.8
	Female	780	66.0
Highest level of education	Primary	161	13.6
	Secondary	326	27.6
	College/university	607	51.4
	Other	44	3.7
Employment status	Full time	289	24.5
	Part time	120	10.2
	Volunteer	27	2.3
	Unemployed	436	36.9
	Student	36	3.0
	Retired	241	20.4
Self-reported diagnosis	Depression	604	51.1
	Bipolar disorder	578	48.9
Agreement with diagnosis	Agree	1063	89.9
	Disagree	29	2.5
	Not sure	71	6.0
Age ^b (n = 742)	Mean (SD)	45.67 (12.81)	
Age at first treatment for mental health problem (n = 1156)	Mean (SD)	31.59 (12.39)	
Number of social contacts (range 0–5)	Mean (SD)	3.2 (1.04)	

^a Not all totals equal 1182 (100%) because of missing responses.

^b n = 4 countries (Finland, Sweden, Poland, Croatia) did not collect data on age.

Table 2
Distribution of ISMI, SR, BUES and PDD scores.

	N ^a	Mean	SD	Minimal >2		Low 2–2.5		Moderate 2.5–3		High 3+	
				N	%	N	%	n	%	N	%
ISMI (excludes SR)	1160	1.79	.87	539	45.6	364	30.8	214	18.1	43	3.6
Alienation (A)	1172	2.22	1.09	400	33.8	307	26.0	269	22.8	196	16.6
Stereotype endorsement (SE)	1168	1.59	.78	660	55.8	361	30.5	112	9.5	35	3.0
Discrimination experience (DE)	1167	1.91	.96	487	41.2	412	34.9	115	12.1	113	9.6
Social withdrawal (SW)	1171	1.98	1.00	486	41.1	346	29.3	220	18.6	119	10.1
Stigma resistance (SR)	1167	2.81	0.98	114	9.6	348	29.4	352	29.8	353	29.9
BUES total	1152	2.83	0.83	51	4.3	357	30.2	477	40.4	257	22.6
Self-esteem/self-efficacy (SESE)	1157	3.04	0.95	74	6.3	276	23.4	333	28.2	474	40.1
Power/powerlessness (PP)	1154	2.70	0.91	112	9.5	364	30.8	437	37.0	241	20.4
PDD total	1162	3.00	.89	73	6.2	243	20.6	457	38.7	389	32.9

^a Not all totals equal 1182 because of missing responses.

1113) = 29.77, $p = 0.001$ with Bonferroni adjusted pairwise tests). There was no significant difference in self-stigma scores by gender.

3.3. Differences between countries

For the 13 included countries, mean self-stigma scores ranged from 1.61 (SD = 0.45) in Sweden to 2.36 (SD = 0.40) in Lithuania, with a midpoint mean score of 2.22 (SD = 0.57) in Macedonia. Mean stigma resistance scores ranged from 2.26 (SD = 0.58) in Poland to 2.84 (SD = 0.61) in Finland, with a midpoint mean score of 2.64 (SD = 0.53) in the Greece. Empowerment scores ranged from 2.32 (SD = 0.45) in Croatia to 2.92 (SD = 0.45) in Sweden, with a midpoint mean score of 2.60 (SD = 0.53) in Greece. Perceived discrimination scores ranged from 2.60 (SD = 0.54) in Sweden to 3.13 (SD = 0.57) in Greece, with a midpoint mean score of 2.72 (SD = 0.53) in Spain. There was significant between-country variation on all four measures: self-stigma ($F(12, 1147) = 24.02, p = 0.001$), stigma resistance ($F(12, 1154) = 6.40, p = 0.001$), empowerment ($F(12, 1139) = 15.75, p = 0.001$) and perceived discrimination ($F(12, 1149) = 7.26, p = 0.001$).

3.4. Regression models

Due to the variation between countries described above, the significance levels of univariate and multivariate models

were adjusted using clustering to take account of the differences between countries. Table 3 shows the results of these analyses.

The variables of SESE empowerment, PP empowerment, PDD and SR were recoded as binary variables so the *B* coefficient represents the change in ISMI (binary: minimal/low, moderate/high) when moving from minimal/low to moderate/high levels of each variable. Number of areas of social contact was recoded as a binary variable with the *B* coefficient representing the change in ISMI when moving from having below the median number of areas of social contact (0, 1 or 2) to having the median or higher number of areas of social contact (3, 4, 5).

Age at first contact with mental health services was recoded as a categorical variable with three categories: 1) age 25 or younger, 2) age 26–40, and 3) age 41 or older. Employment and education were included as binary variables, as described in Section 2.7.

A reduced model including only self-esteem/self-efficacy, power/powerlessness, perceived discrimination, number of areas of social contact, education and employment status as independent variables predicted 27.3% of the variance in self-stigma scores. Diagnosis of bipolar disorder (compared with diagnosis of depression) and age at first contact with mental health services were not included in this model as they were not significant predictors in the univariate analyses. As seen in Table 3, significant associations were found for moving

Table 3
Combined logistic regression model of self-stigma clustered by country. Dependent variable is ISMI score (binary) (0 = minimal/low, 1 = moderate/high).

Independent variables	Univariate models ($n = 1066-1117$)					Multivariate model ($n = 1001$) ^a Wald $\chi^2 = 330.92, p < 0.001$ Pseudo $R^2 = 0.273$				
	<i>B</i> Coef	OR	95% CI	p^a		<i>B</i> Coef	OR	95% CI	p^a	
Mod/high perceived discrimination (binary)	1.30	3.66	2.29	5.85	<0.001	0.86	2.36	1.38	4.06	<0.001
Mod/high SESE empowerment (binary)	-1.74	0.17	0.12	0.25	<0.001	-1.22	0.29	0.21	0.41	<0.001
Mod/high PP empowerment (binary)	-1.80	0.17	0.11	0.25	<0.001	-1.42	0.24	0.15	0.39	<0.001
Mod/high stigma resistance (binary)	-0.98	0.38	0.24	0.60	<0.001	-0.39	0.68	0.39	1.17	0.17
Social contacts (binary)	-0.54	0.59	0.48	0.72	<0.001	-0.37	0.69	0.58	0.83	<0.001
University education (binary)	-1.09	0.34	0.21	0.56	<0.001	-0.75	0.47	0.31	0.72	<0.001
Employed (binary)	-0.77	0.46	0.32	0.66	<0.001	-0.46	0.63	0.46	0.87	0.01
Diagnosis of bipolar disorder (binary)	-0.45	0.64	0.35	1.18	0.15					
Age at FCMHS ^b										
26–40	-0.03	0.97	0.73	1.28	0.82					
41+	-0.24	0.78	0.47	1.30	0.35					

^a Standard errors are adjusted for clustering (13 countries). $p =$ value unless < specified.

^b FCMHS = first contact with mental health services. Compared with category of 25 or younger.

from minimal/low to moderate/high perceived discrimination (OR = 2.36, CI: 1.38–4.06 $p < 0.001$), minimal/low to moderate/high self-esteem/self-efficacy (OR = 0.29, CI: 0.21–0.41 $p < 0.001$), moving from minimal/low to moderate/high power/powerlessness (OR = 0.24, CI: 0.15–0.39 $p < 0.001$), moving from below the median to median or greater number of areas of social contact (OR = 0.69, CI: 0.58–0.83 $p < 0.001$), university education compared with other education (primary school/secondary school or apprenticeship) (OR = 0.47, CI: 0.31–0.72 $p < 0.001$), and employed compared with not employed (OR = 0.63, CI: 0.46–0.87 $p = 0.01$). Moving from minimal/low to moderate/high stigma resistance was not a significant independent predictor of self-stigma in this model. The Hosmer–Lemeshow test was non-significant indicating good fit of this model ($X^2 = 0.96$ (10, $n = 1001$), $p = 0.97$).

4. Discussion

This study examined the degree to which individuals with a diagnosis of bipolar disorder or depression report self-stigma in 13 European countries. Over one fifth of participants (21.7%) reported moderate or high levels of self-stigma. The large majority of participants felt that the public hold negative attitudes towards people with a mental illness (71.6% reported moderate to high levels of perceived discrimination). The degree to which this belief was held was associated with the greatest change in reported self-stigma in the clustered multivariate model. This suggests a strong association between perceptions of the outside world and representations within the internal world by study participants. However, many people who perceived that the public hold negative attitudes towards people with a mental health problem and discriminate against them (perceived stigma) don't apply these devaluing sentiments to themselves (self-stigma). This highlights the conceptual distinction between self-stigma and perceived stigma and emphasises the importance of regarding this conceptual distinction and choosing an appropriate measure.

In keeping with previous studies using the ISMI participants had the lowest scores for the stereotype endorsement subscale (Brohan et al., in press; Lysaker et al., 2008; Ritscher et al., 2003; Sibitz, et al., 2009). This suggests that internalising stereotypes or accepting diminished expectations for oneself, e.g. "Because I have a mental illness, I need others to make most decisions for me", was not particularly frequently reported, with 86.4% of participants reporting minimal to low levels. This also has important implications for the concept of self-stigma. Self-stigma is typically defined as accepting diminished expectations or applying stereotypes to oneself. However, this study emphasises the finding of previous research that this is actually the least frequently endorsed aspect of the construct. In this study, alienation was the most frequently endorsed subscale (39.3%), followed by social withdrawal (28.7%) and discrimination experience (22.7%). This suggests that a feeling of 'separateness' may be useful to consider in relation to self-stigma.

Empowerment, a higher number of areas of social contact, university education and being employed were all significantly associated with lower self-stigma scores. Within empowerment, 68.3% had moderate to high self-esteem/self-efficacy scores and 57.4% had moderate to high power/

powerlessness scores. Both subscales had adequate internal consistency within this sample. Stigma resistance was not a significant independent predictor of self-stigma. 59.7% of the sample reported moderate to high levels of stigma resistance. All scales had adequate internal consistency with the exception of the stigma resistance subscale ($\alpha = 0.59$). This supports the suggested need for further work to develop this into an independent scale (Sibitz et al., 2009).

Those with a diagnosis of depression had significantly higher self-stigma scores than those with a diagnosis of bipolar disorder (mean score 2.11 vs. 1.94, $t = 1.56$, $p = 0.001$). As alienation is the most highly endorsed element of self-stigma, this is in keeping with evidence that the public desire less social distance from people with bipolar disorder than from people with depression (Feldman and Crandall, 2007). However, diagnosis was not a significant independent predictor in our regression analyses. In our previous study examining self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries, 41.7% of participants ($n = 1229$) reported moderate to high levels of self-stigma which is somewhat higher than the rate of 21.7% reported in this current study (Brohan et al., in press). This further suggests that individual with schizophrenia may experience greater self-stigma than individuals with depression who may experience greater self-stigma than individuals with bipolar disorder. Further research to examine the impact of other indicators of illness severity and visibility, such as having received compulsory treatment, number of years since first contact with mental health services, level of role and social functioning, level of depression, having experienced 'visible' side-effects of medication and having experienced 'visible' illness symptoms may help to further tease out the relationship between diagnosis and self-stigma.

5. Limitations of the study

This study was designed to provide evidence on the levels of self-stigma across Europe. The large proportion of our sample reported some university or college education (51.4%). As shown in this current study, and in previous studies, education is associated with lower reported self-stigma (Werner et al., 2009; Yen et al., 2005). This suggests that our sample may have lower levels of self-stigma than typically present in individuals with these diagnoses.

As a survey of members of mental health charity organisations, one could argue that these participants are more comfortable with the identity of mental health service user than individuals who are not involved in such activities. As discussed in our previous paper, it may also indicate that they are adopting a stigma coping strategy based on educating others or on advocacy rather than one based on secrecy or avoidance (Brohan et al., in press). Adopting a coping style based on withdrawal or secrecy has been significantly associated with greater self-stigma (Vault et al., 2007). This suggests participants in our study may have lower self-stigma and higher empowerment than typically present in individuals with these diagnoses. Alternatively, it may also be the case that people who experience greater levels of self-stigma may have a higher level of identification with other mental health service users and or may feel more compelled to join in a collective action such as

joining a charity organisation. Although it is not possible to compare our scores to others obtained in the countries studied due to a lack of published literature, our self-stigma scores are comparable with published scores from the US. Conner and colleagues reported mean ISMI (including SR) as 2.14 (SD = 0.36), when calculated in this way our score is 2.07 (SD = 0.50) (Conner et al., 2010). Brown and colleagues reported a summed total of all ISMI items (including SR) as 65.5 (SD = 11.2) (Brown et al., 2010). Our score for this calculation is 61.19 (SD = 13.79).

A number of other potential limitations of this study are discussed in a previous paper (Brohan et al., in press). These relate to the translation procedure, cross-cultural interpretations of the survey, differing response rates between organisations and the fact that data were not weighted to take account of country size and number of returned surveys.

6. Conclusions

These findings suggest that approximately one fifth of people with bipolar disorder or depression experience moderate to high levels of self-stigma across 13 European countries. High levels of perceived discrimination and empowerment were reported. This supports the conclusions of our previous study, that further attention should be paid to tailoring self-stigma interventions to support the elements of self-stigma which are most problematic for the group, be they alienation, stereotype endorsement, social withdrawal or discrimination experience. The association between self-stigma and empowerment, number of areas of social contact, education and employment generates the future hypothesis that interventions to enhance these factors may have a role in reducing self-stigma. Further research is needed to examine the impact of interventions targeted towards the general public and individuals with a bipolar disorder or depression on reducing self-stigma. Mass media campaigns to challenge public stigma, e.g. (Henderson and Thornicroft, 2009), provide an opportunity to examine the degree to which reductions in public stigma are associated with reductions in self-stigma and perceived stigma at several timepoints.

There is initial evidence that individuals with bipolar disorder experience less self-stigma than those with schizophrenia or depression. However, this finding requires confirmation from samples more representative of clinical or general population sampling frames.

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Conflict of interest

All authors declare they have no conflicts of interest relevant to the preparation of the manuscript.

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References

- Alonso, J., Buron, A., Rojas, S., de Graaf, R., Haro, J.M., de Girolamo, G., Bruffaerts, R., Kovess, V., Matschinger, K., Vilagut, G., 2009. Perceived stigma among individuals with common mental disorders. *Journal of Affective Disorders* 118 (1), 180–186.
- Barney, L., Griffiths, K., Christensen, H., Jorm, A., 2009. Exploring the nature of stigmatising beliefs about depression and help-seeking: implications for reducing stigma. *BMC Public Health* 9 (1), 61.
- Brohan, E., Slade, M., Clement, S., Thornicroft, G., 2010. Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC Health Services Research* 10 (1), 80.
- Brohan, E., Elgie, R., Sartorius, N., Thornicroft, G., 2010. Self-stigma, empowerment and perceived discrimination among people with schizophrenia in 14 European countries: The GAMIAN–Europe study. *Schizophrenia Research* 122, 232–238.
- Brown, C., Conner, K.O., Carr Copeland, V., Grote, N., Beach, S., Battista, D., Reynolds, C.F.I., 2010. Depression stigma, race, and treatment seeking behavior and attitudes. *Journal of Community Psychology* 38 (3), 350–368.
- Conner, K.O., Copeland, V.C., Grote, N.K., Koeske, G., Rosen, D., Reynolds, C.F.I., Brown, C., 2010. Mental health treatment seeking among older adults with depression: the impact of stigma and race. *American Journal of Geriatric Psychiatry* 18 (6), 531–543.
- Corrigan, P.W., Watson, A.C., 2002. The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice* 9 (1), 35–53.
- Feldman, D.B., Crandall, C.S., 2007. Dimensions of mental illness stigma: What about mental illness causes social rejection? *Journal of Social and Clinical Psychology* 26 (2), 137–154.
- Fung, K.M., Tsang, H.W., Corrigan, P.W., Lam, C.S., Cheung, W.M., 2007. Measuring self-stigma of mental illness in China and its implications for recovery. *International Journal of Social Psychiatry* 53, 408–418.
- Gabriel, A., Violato, C., 2010. The development and psychometric assessment of an instrument to measure attitudes towards depression and its treatments in patients suffering from non-psychotic depression. *Journal of Affective Disorders* 124 (3), 241–249.
- GAMIAN–Europe. 2007. <http://www.gamian.eu/>.
- Hayward, P., Wong, G., Bright, J.A., Lam, D., 2002. Stigma and self-esteem in manic depression: an exploratory study. *Journal of Affective Disorders* 69, 61–67.
- Henderson, C., Thornicroft, G., 2009. Stigma and discrimination in mental illness: time to change. *The Lancet* 373 (9679), 1928–1930.

- Kanter, J.W.P., Rusch, L.C.M., Brondino, M.J.P., 2008. Depression self-stigma: a new measure and preliminary findings. *Journal of Nervous & Mental Disease* 196, 663–670.
- Lim, L., Nathan, P., O'Brien-Malone, A., Williams, S., 2004. A qualitative approach to identifying psychosocial issues faced by bipolar patients. *The Journal of Nervous and Mental Disease* 192 (12), 810–817.
- Link, B.G., 1987. Understanding labeling effects in the area of mental disorders: an assessment of the effect of expectations of rejection. *American Journal of Community Psychology* 11, 261–273.
- Link, B.G., Mirotznic, J.D., Cullen, F.T., 1991. The effectiveness of stigma coping orientations: can negative consequences of mental illness labeling be avoided? *Journal of Health and Social Behavior* 32, 302–320.
- Lysaker, P.H., Roe, D., Yanos, P.T., 2008. Towards understanding the insight paradox: internalised stigma moderates the association between insight and social functioning, hope and self-esteem among people with schizophrenia spectrum disorders. *Schizophrenia Bulletin* 33 (1), 192–199.
- Manos, R.C., Rusch, L.C., Kanter, J.W., Clifford, L.M., 2009. Depression self-stigma as a mediator of the relationship between depression severity and avoidance. *Journal of Social and Clinical Psychology* 28 (9), 1128–1143.
- Michalak, E.E., Yatham, L.N., Kolesar, S., Lam, R.W., 2006. Bipolar disorder and quality of life: a patient centred perspective. *Quality of Life Research* 15, 25–37.
- Morselli, P.L., Elgie, R., 2003. GAMIAN-Europe BEAM survey I – global analysis of a patient questionnaire circulated to 3450 members of 12 European advocacy groups operating in the field of mood disorders. *Bipolar Disorders* 5, 265–278.
- Perlick, D.A., Rosenheck, R.A., Clarkin, J.F., Sirey, J.A., Salah, J., Struening, E.L., Link, B.G., 2001. Stigma as a barrier to recovery: adverse effects of perceived stigma on social adaptation of persons diagnosed with bipolar affective disorder. *Psychiatric Services* 52 (12), 1627–1632.
- Pyne, J.M., Kuc, E.J., Schroeder, P.J., Fortney, J.C., Edlund, M., Sullivan, G., 2004. Relationship between perceived stigma and depression severity. *The Journal of Nervous and Mental Disease* 192 (4), 278–283.
- Raguram, R., Weiss, M.G., Channabasavanna, S.M., Devins, G.M., 1996. Stigma, depression, and somatization in South India. *American Journal of Psychiatry* 153 (8), 1043–1049.
- Ritsher, J.B., Phelan, J.C., 2004. Internalized stigma predicts erosion of morale among psychiatric outpatients. *Psychiatry Research* 129, 257–265.
- Ritsher, J.B., Otilingam, P.G., Grajales, M., 2003. Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Research* 121 (1), 31–49.
- Roeloffs, C., Sherbourne, C., Unutzer, J., Fink, A., Tang, L., Wells, K., 2003. Stigma and depression among primary care patients. *General Hospital Psychiatry* 25, 311–315.
- Rogers, E.S., Chamberlin, J., Ellison, M.L., Crean, T., 1997. A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Services* 48 (8), 1042–1047.
- Rusch, L.C.M., Kanter, J.W.P., Manos, R.C.M., Weeks, C.E.M., 2008. Depression stigma in a predominantly low income African American sample with elevated depressive symptoms. *Journal of Nervous & Mental Disease* 196, 919–922.
- Sartorius, N., Kuyken, J., 1994. Translation of health status instruments. In: Orley, J., Kuyken, J. (Eds.), *Quality of Life Assessment in Health Care Settings*, vol. 1. Springer-Verlag, Berlin.
- Sibitz, I., Unger, A., Woppmann, A., Zidek, T., Amering, M., 2009. Stigma resistance in patients with schizophrenia. *Schizophr Bull* [Epub ahead of print]. doi:10.1093/schbul/sbp048.
- Sirey, J.A., Bruce, M.L., Alexopoulos, G.S., Perlick, D.A., Friedman, S.J., Meyers, B.S., 2001. Stigma as a barrier to recovery: perceived stigma and patient-rated severity of illness as predictors of antidepressant drug adherence. *Psychiatric Services* 52, 1615–1620.
- Vauth, R., Kleim, B., Wirtz, M., Corrigan, P., 2007. Self-efficacy and empowerment as outcomes of self-stigmatizing and coping schizophrenia. *Psychiatry Research* 150, 71–80.
- Werner, P., Stein-Shvachman, I., Heinik, J., 2009. Perceptions of self-stigma and its correlates among older adults with depression: a preliminary study. *International Psychogeriatrics* 21 (06), 1180–1189.
- Yanos, P.T., Roe, D., Markus, K., Lysaker, P.H., 2008. Pathways between internalised stigma and outcomes related to recovery in schizophrenia spectrum disorders. *Psychiatric Services* 59 (12), 1437–1442.
- Yen, C.F., Chen, C.C., Lee, Y., Tang, T.C., Yen, J.Y., Ko, C.H., 2005. Self-stigma and its correlates among outpatients with depressive disorders. *Psychiatric Services* 56 (5), 599–601.